

Health Citizenship:
Exploring Community, Health and Geography
in the context of the Anxiety Disorders
Association of Ontario.

Ruth Bankey

PhD Thesis

The University of Edinburgh

Geography

School of GeoSciences

Drummond Street

Edinburgh EH8 9XP

July 2004



Contents

Abstract	I
Acknowledgements	III
Declaration	IV
Chapter One Introduction	1
Chapter Two Literature Review	12
Chapter Three Methodology	45
Chapter Four Background Chapter: A Brief History of the ADAO	75
Chapter Five Body: 'Imagining' Panic	94
Chapter Six Mind: Governing Panic	123
Chapter Seven Heart: Connecting the Self	148
Chapter Eight Breath: Spaces of Citizenship - Connecting the Organization	172
Chapter Nine- Conclusions	197
Appendices	214
Bibliography	224

Health Citizenship: Exploring Community, Health and Geography in the context of the Anxiety Disorders Association of Ontario.

Abstract

The Anxiety Disorders Association of Ontario (ADAO) is a grassroots, 'community' based group that seeks to readdress the lack of figurative and literal spaces available for those with anxiety conditions such as panic and agoraphobia. In order to do so, the ADAO must negotiate a balance between networking with other organizations, and maintaining its own direction, thereby creating a space that is 'one's own'. Using qualitative methods this thesis examines how the ADAO constructs itself in the context of this tension.

The thesis builds on geographical, feminist and political literatures about the interrelationship between health, identity, space and place by focusing on experiences of anxiety conditions that are embodied by members of the ADAO. The thesis illustrates the complex interconnections between discourses of community, identity, and wider socio-economic, political and medical environments. More specifically the thesis investigates the discursive production of mental health care spaces and services for anxiety conditions within Ottawa, Ontario, Canada.

Chapter one introduces the questions that the thesis addresses and the theoretical perspectives that inform it. Chapter two reviews current work in the social sciences and geography on anxiety conditions and agoraphobia in particular; feminist political theory on issues of care and autonomy; and geographical research on health care, mental health, disability and impairment. Chapter three explains how the research was informed by feminist geographical methodologies, and how the data were collected, used, analyzed and written within the research process. Chapter four provides an account of the history of the ADAO and the context within which it operates.

The next four chapters analyse documentary and interview data to show how the ADAO advocates the development of 'health citizenship' as opposed to a model of the normative 'healthy citizen' upon which much clinical organization and health care practice is based. The healthy citizen-subject is an abstract ideal created and maintained by processes of governmentality, expert knowledges and a self-care ethic that shapes wider beliefs about who is an effective, productive member of society. Health citizenship by contrast highlights the needs and lived experiences of individuals, including those with anxiety conditions. It

incorporates people's experiences into a model of citizenship and subjectivity rather than using experiences like anxiety as something to strive against. Consequently, rather than negating one's own experience of ill health in the pursuit of an ideal of an 'able', sickness-free, body and subjectivity, the experience of ill health becomes a constituent part of citizenship. Thus, the thesis argues that, through the development of health citizenship, the ADAO offers an inclusive model of subjectivity and community consistent with geographies of active citizenship and radical democracy. In this way the ADAO forges a space for itself within a landscape of mental health service provision. Chapter nine concludes the thesis by summarising its core argument and emphasizing the importance of the knowledges of those with anxiety conditions including 'community' groups such as the ADAO, which so often remain excluded from wider debates about health-care provision; highlighting the thesis' contribution to the production of geographical, political, and feminist knowledge and theory with a focus on the contributions the thesis has made to the subject of geography; and suggestions for future research directions and questions.

Acknowledgements

I would like to thank Prof. Liz Bondi for her continued support, insight, editing and practical work as a supervisor work throughout the process of thinking about, researching and writing up the doctorate. Certainly without Liz Bondi's practical and editorial work this thesis would not have been possible. I would also like to thank Dr. Kim Hutchings for her support, editorial work and insight throughout the thesis process. There have been other individuals who have also contributed at different points to the research process. I would like to thank Dr. Lynda Johnson for her assistance and support of the thesis work in its earlier stages and work on the ethical review process, as well as Dr. Marilyn Kendall for her assistance on the ethics review component of the thesis. I would also like to thank Dr. Fiona Mackay and Dr. Hester Parr for their suggestions, feedback and comments on the thesis work. All these women have contributed to my growth as a researcher, feminist, academic and person and for that I thank them enormously.

It is also important to acknowledge everyone who formally and informally participated in this research and contributed to the development of knowledges. I would like to thank the Anxiety Disorders Association of Ontario for the provision of materials, access to information and network of interviewees. In particular I would like to thank Cheryl Driskell, former Executive director of the ADAO for her support throughout the research process. Brian, thank you too.

Chapter One - Introduction

1.1 Thesis themes and issues

In *Anxiety in a Risk Society* Iain Wilkinson (2001) describes how anxiety has become a central trope within contemporary cultural and social theory. The twentieth century has been an 'age of anxiety', a time of high anxiety resulting in increasing vulnerability and instability. It is not surprising then that anxiety disorders, which emerged as a clinical category within the later nineteenth and throughout the twentieth century, are seen by some as a quintessential marker of modernity (Freud, 1979 in Wilkinson, 2001). For cultural theorists such as Kroker and Cook (1985) and Bauman (1993), anxiety and panic characterize the postmodern state of mind and the postmodern condition (Bauman, 1993). For social theorists such as Beck (1992) and Giddens (1991), anxiety underpins the concept of the risk society. In a world that is characterized as increasingly risky, anxiety is inevitable (Beck, 1992).

According to numerous studies anxiety disorders are the most prevalent form of mental condition within western societies. It is estimated that one out of every six persons will have an anxiety disorder at some point in their life, and that these statistics may be higher for women than men. Anxiety conditions include panic disorder, agoraphobia with and without panic, post-traumatic stress disorder, phobias including specific and social phobias, obsessive-compulsive disorder, and generalized anxiety disorder (APA, 2000; NIMH, 2003). Throughout the thesis I typically use the term 'condition', rather than the conventional term 'disorder' to complicate clinical language practices, as well as a respectful gesture to the subjects of my research who highlight the stigmatizing effects of the term 'disorder'. However, the term disorder is used, where appropriate, as a way of making specific reference to clinical discourses.

In spite of the discussion of the importance and prevalence of anxiety, there is very little development of what anxiety means and how it is experienced. This thesis aims to address that gap. While there is considerable and growing interest in the subject of anxiety, panic and agoraphobia within clinical literatures, there are few writings on these subjects within the social sciences and humanities that address the lived realities of these conditions, and even fewer writings on organizations that deal with these issues. Writings on anxiety, panic and agoraphobia have been primarily concerned with individual experiences and

stories. This is because these narratives have historically been silenced or remained unheard and unspoken. This thesis aims not only to investigate the experiences of individuals but, to explore a different kind of storyteller, one who has also been largely unheard and silenced - the anxiety organization.

The wider aims/purposes of the thesis are: First, to highlight the importance of organizations that address anxiety conditions because these groups often remain unacknowledged or subjugated within the health service sector. Thus, the thesis illustrates the relevance that anxiety organizations, and the experiences of its membership, have for further study. Second, to provide geographical insights of relevance to the experience of individuals with anxiety conditions and groups that deal with anxiety conditions. And third, to contribute to, and expand on, geographical, feminist and political theory by illustrating the connections between geography, embodied experiences of anxiety, mental health service provision and the negotiation of identity, community and citizenship. This thesis seeks to advance several different areas of geographical inquiry including work on mental health and health geography, geographies of fear, geography and the body, the public/private divide, the geography of community and citizenship.

The research uses an intensive case study of a particular voluntary organization – the anxiety disorders association of Ontario (ADAO). The thesis revolves around the experiences of the ADAO and its membership from 1999 - 2002. The ADAO is a non-profit/ voluntary/grassroots/charitable/sufferer-led/‘community based’ organization located in Ottawa, Ontario, Canada with a mandate to provide information, increase awareness and offer educational services to those with anxiety conditions and the wider public. Organizations like the ADAO were developed in response to the lack of public spaces and forums available for those with anxiety conditions. The ADAO aims to readdress this imbalance and inequality for those with anxiety conditions. It seeks to actively create a place, literally and figuratively, that works with, and is based on, the lived realities of those with anxiety conditions. In order to do so an effective anxiety and panic organization needs to negotiate the balance between networking with others and the development of its own direction. This process is always ongoing as: “a fully inclusive (political) community and its final unity can never be realized since their will permanently be a ‘constitutive outside’, an exterior to the community that makes its existence possible” (Mouffe, 1993:235). The ADAO wants to carve its own space within the wider context of

health service provision and other communities, while simultaneously creating and sustaining productive networks and communicative relationships within that wider context that will encourage the organizations growth. The thesis explores this ongoing process for the ADAO and identifies the organization's difficulties and successes in negotiating its place within, and as, a community.

The ADAO exists within a series of interconnected tensions that affect both individuals and the development of the organization itself, both of whom are trying to find a place for themselves within their wider contexts. These tensions reflect wider societal issues about the place of 'mental health' and the prioritization of knowledge within a health care system. They also open up some important questions about the relationship between service provision, subjectivity and community, thus exploring these tensions has wider relevance for theory, potential service provision and organizational development. The tensions center around the pathologization of anxiety conditions and anxiety service provision, as well as the creation of alternate knowledges about anxiety conditions that focus on the daily lived realities of anxiety conditions and services that directly address those experiences, which may contradict or complicate clinical practices and knowledges of anxiety disorders. Both individuals and groups must weigh the costs and benefits of being labeled with a mental disorder. What are the costs of the stigmatization of mental illness on the subjectivities, identities and geographies of individuals and groups that deal with anxiety conditions? In a health care system that is dominated by clinical structures, power and knowledge can groups and individuals afford not to enter into this system and risk being positioned outside, without access to needed services, funding or recognition.

The thesis also argues for an understanding of anxiety conditions, and the grassroots organizations that address these issues, as significant in comprehending processes of subjectivity. In particular the thesis argues that anxiety organizations may offer alternative models of subjectivity that affect our sense of community and help us position ourselves within wider geographical, socio-cultural and clinical contexts. Thus the thesis uses the case study of the ADAO in order to illustrate different forms of subjectivity negotiated and produced within its programs and discourses, specifically what I describe as the healthy citizen and health citizenship.

The experience of anxiety, similar to other mental health conditions, is often a marker of the anti-citizen; that to which we should not aspire to become. The experiences of those with anxiety disorders rather than being incorporated into a collective notion of subjectivity and citizenship becomes a marker of lack, the antithesis of the contemporary citizen, something that is worked against as opposed to worked with. To have anxiety is normal and routine, to succumb to anxiety is a sign of weakness, an inability to cope with societal demands; thus anxiety disorders signal a character flaw, connected to the essential self and nature of that person (Wilkinson, 2001). Anxiety is something that people can and should be able 'to get over' and 'move on from'. Anxiety conditions are classified as neuroses, which means a relatively mild mental illness involving symptoms of stress without loss of contact with reality (APA, 2000). In this way sufferers are seen to have some control over their actions and are thought of as responsible agents who are liable for maintaining control of themselves and coping with their surroundings. However, many sufferers describe feeling overwhelmed and losing control of themselves and their environments during an anxiety or panic attack. Thus, the sufferer takes on the double burden of feeling as if they are losing control, yet as responsible agents they are liable for themselves and their actions. In this way anxiety disorders, such as panic, become markers of vulnerability and instability, associated with the history of labeling mental illness and madness. This creates a cycle of self doubt and self blame, in which feelings of shame, deviance, abnormality lead to a process of physically and metaphorically isolating and 'othering' the self.

The stigmatization of anxiety has resulted in misperceptions about the severity and experience of anxiety that have further led to the invisibility, trivialization and marginalization of anxiety conditions as being just 'anxious' or 'panicky'. The misperceptions and trivialization of anxiety conditions are issues that the ADAO must address in order to gain credibility for its cause, to increase awareness and educate the public. Therefore the ADAO must address the issue of subjectivity and become active in its (re) construction. However the process by which the ADAO negotiates subjectivity is both complex and contradictory. On the one hand the ADAO actively fosters the needs and lived experiences of individuals with anxiety conditions and incorporates those experiences into a model of citizenship and subjectivity rather than using those experiences as something to strive against. In this thesis this is described as health citizenship. Within a model of health citizenship the experience of ill health becomes a

constituent part of citizenship as opposed to its antithesis. On the other hand, the pursuit of an ideal 'able', sickness free body and subjectivity is central to both the clinical care system and the ADA which often bifurcates the experience of ill health in favor of an end product, what is described in the thesis as the healthy citizen.

The thesis argues that the question of organization development is necessarily connected to the issue of subjectivity. I argue that an organization that is able to balance alternative discourses in the wider context of clinical structures without losing sight of its own desires and goals is an organization that strives towards developing health citizenship as opposed to reifying the ideal of the 'healthy' citizen. In other words rather than negating ones' own experience of ill health in pursuit of the ideal of a 'sickness free' body and subjectivity, the experience of ill health becomes a constituent part of citizenship. Health citizenship is similar in many respects to cultural citizenship, which values and includes a diverse range of cultural identities and cultural practices into a model of the citizen. Similar to Anne Phillips (1995) "politics of presence", in which she discusses cultural citizenship, health citizenship is attentive not simply to the messages but to the messengers themselves. But unlike cultural citizenship, which is more concerned with identity politics, health citizenship is concerned with body politics. Thus, embodied subject positions, the spaces of the body, and the relationship of the body to wider geographies then must be taken into consideration within the development of what constitutes citizenship and what kinds of considerations need to be made in thinking about citizen-subjects.

Susan Sontag (1978) goes one step further than Phillips by provocatively suggesting that illness and ill health itself is a more onerous form of citizenship. Though it is a statement that she throws out, with little additional discussion, I believe she is implying that the notion of an able body upon which normative theories of citizenship are based should be abandoned in favor of a body that experiences ill health. For her it is more realistic that at some point we will all experience, in some form or another, illness; and less likely that most of us will be able to attain the ideal of the abstract 'able' body based on universalized principles that privilege a particular type of (male) body to begin with. I believe Sontag is implying suffering, whether it is physical, emotional, mental, economic or otherwise, needs to be a constitutive part of the concept of citizenship as opposed to its antithesis. Thus, illness as a more onerous form of citizenship also requires that we take

more seriously experiential aspects of health and health service provision. Here the subject of health citizenship is not the possibility of some abstracted ideal to be attained separate from personal reality, but something that addresses the everyday realities of ill health. The thesis does not imply that health citizenship should not involve the desire and the aspiration to 'get better' and 'be well', but that in the pursuit of health, the process of getting better (which may also involve getting worse) is often ignored in favor of the end destination, meaning that the experience of ill health is often compounded with a lack of service provision, care and rights accorded to those individuals when they are 'unhealthy'. Additionally, in the case of chronic illness, which is common for many of those with anxiety conditions, there are some people who will never 'get better', and what options are those persons left with for enhancing their sense of personhood and subjectivity?

Health citizenship can involve looking for alternative radical democratic spaces of citizenship; become a process of community development and organization; or become a process in which radical change may not occur, but where citizens gain a sense of their relationship and needs in relation to social institutions and an appreciation that those institutions are not natural but subject to construction. Within the thesis these understandings of citizenship are linked and enhance an understanding of the other. In these discursive conceptions of citizenship one comes to realize one's place relative to the ideal of citizen, as well as, one's lack of place in relation to the ideal. The thesis is concerned to discover how looking at the geographies of citizenship means looking for different expressions of citizenship beyond the public-private divide, especially when considering anxiety conditions such as agoraphobia. Health citizenship is a process where people are positioned in complex ways that may help to resist or subvert existing meanings and spaces of the political, extending meanings of the political beyond that of the 'state'.

The tension between models of the healthy citizen and health citizenship are reflective of the tension the ADAO has in balancing its desire to create a space for itself and to network with other anxiety service providers. By focusing on issues of health citizenship and the healthy citizen the thesis is concerned to discover how organizations such as the ADAO come to affect the construction of identity, subjectivity and community in ways that suggest the importance of the first hand experiences and narratives of those with anxiety conditions, panic and agoraphobia in particular. The issue of health citizenship is

linked within this thesis to a number of central questions about the capacity of an organization to develop new frameworks of knowledge, subjectivity and identity. Does the ADAO create spaces it can call its own offering new alternatives? Is this important or useful for the ADAO to do so in the first place? In creating these alternative venues does the ADAO also contribute to the development of productive ways of thinking about anxiety conditions? Does the ADAO seek to replicate and develop its membership as healthy citizens, who can be slotted back into their contexts so as to be productive and effective workers and citizens? Or is the ADAO concerned to include the lived realities of anxiety conditions into the model of subjectivity and engage in a process of health citizenship?

1.2 Chapter Structure

The first four chapters, including this one, set up the substantive analysis for chapters five through eight. Chapter two is a literature review of non-clinical and geographical writings on anxiety conditions, in particular panic and agoraphobia, the two anxiety conditions that will be primarily focused on within this thesis. Chapter three is concerned with the research methodologies employed during the thesis process and within a broader discussion of feminist geographical methodology. The fourth chapter provides background material and an organizational history of the ADAO that helps to contextualize the normative, geographical and social theory to follow. Chapters five through eight elaborate on different but connected issues that develop the central questions of the thesis.

The main substantive section of the thesis, chapters five to eight, reflects the ongoing tensions and questions within the ADAO about the negotiation of its identity, subjectivity and community. In this section 'body' (chapter 5), 'mind' (chapter 6), 'heart' (chapter 7) and 'breath' (chapter 8) chapters structure the main arguments and substantive analysis of the thesis. The metaphoric titles 'body' and 'mind' are used to remind the reader of the legacy of Cartesian dualisms in structuring our subjectivities, identities and communities, while 'heart' and 'breath' are different kinds of metaphors that highlight connectedness rather than categorization. The chapter titles reflect several tensions that the ADAO has to deal with: first, the abstract categorization and understanding of bodies and subjects in comparison to the messy daily-lived realities of anxiety; and second mediating the desire

to be a part of the wider clinical care system that may not reflect the visions and desires of the organization itself.

Chapter five, 'body', explores an aspect of the healthy citizen that is central to its maintenance- the construction of a body that is made intelligible through visual monitoring and the 'gaze'. This contributes to the production of a body, and self, understood through continual self surveillance and regulation. In this respect visibility becomes a component of the spatial reproduction of 'madness' and 'disorder'. These issues are explored through an analysis of how being (in)visible is a central problem and topic for the ADAO, and how this has contributed to the organization's difficulties and the difficulties of many of its membership, both literally and metaphorically.

Chapter six, 'mind', involves another central issue pertinent to the creation of the healthy citizen- the function of expert knowledge, professional discourses and the reliance on that expertise. The metaphor of 'mind' in relation to this issue addresses dilemmas generated by the of the meanings, stigma and "object" of 'mental' illness or disorder within anxiety service provision (Foucault, 1967). Chapter 'mind' focuses on two issues. First, the effects that the stigma of mental disorder, developed in conjunction with the various meanings ascribed to madness, has had on the ADAO and on persons with anxiety conditions. Second, how the ADAO is structured in relation to expert knowledge and how it has adopted expertise into organizational structure, language practices and mandate, thus, at times, privileging professional discourses over 'lay' discourses.

Chapter seven, 'heart', reflects more critically on whether the ADAO simply replicates the dominant normative and social discourses of the healthy citizen, or is actively engaged in the construction of a different kind of subjectivity. The chapter argues that what differentiates the ADAO's programs and mandate is its focus on fostering relational autonomy, the understanding that the creation of the subject is not independent from other people and the context in which the individual is positioned. The focus on the relational nature of identity and subjectivity, or between self and other, helps create a different kind of space which is more responsive to the first hand needs of individuals with anxiety conditions and those around them. A focus on relational autonomy also offers suggestions as to how groups can create different kinds of democratic places that act as alternatives to the dominant spaces of current anxiety service provision and care.

Chapter eight, 'breath', poses the question: can the ADAO be thought of as active in the production of forms of citizenship and democratic spaces that enhance what I have described as health citizenship? The chapter explores in detail how health citizenship is connected and negotiated by the ADAO. The chapter draws on the work of a variety of political and geographical theorists to draw out meanings of health citizenship. Through exploring this issue, the chapter shows how new spaces of health citizenship are useful for organizations (such as the ADAO) and the subjectivities, identities and geographies of those with anxiety conditions.

This substantive section - chapters five through eight are divided into two broad but interconnected sections. Chapters 'body' and 'mind' revolve around how the ADAO has predominantly incorporated but sometimes resisted dominant clinical discourses into its programs, structure and mandate, i.e. creation of a specific body subject to particular forms of (self) governance and (self) surveillance connected to the role of experts and expertise. These chapters connect those clinical discourses to the binary of body/mind, hence the chapter titles, and explore the struggles, challenges or opportunities the ADAO has been presented with as a result of that binary, and how these binaries have been worked into the ADAO's programs, structure and mandate. In this way the chapters highlight that dualistic thinking about body and mind, in spite of academic and theoretical criticism, remain powerful markers in people's everyday lives concerning matters of health and political thought.

Chapters 'heart' and 'breath' analyze in more detail how the ADAO has created a space for itself, its own sense of place, identity and community within the broader local and national context. These chapters focus on how the ADAO has created a literal and metaphoric space for itself that is centered on an understanding of the painful lived realities of anxiety conditions that need to be incorporated in the construction of a more enabling subjectivity, identity and mobility, as opposed to striving towards a particular ideal. Thus, these chapters highlight the possibilities of subverting and transforming the bodies and expert knowledges that sustain certain clinical discourses and practices.

The chapter structure is about a movement from discourses within 'the clinic', the dominant set of bio/logical practices and knowledges created within and emanating from

the professions of biomedicine and 'psy' disciplines that are based on the ideal of the healthy citizen (Foucault, 1980b); to discourses that are structured in relation, in opposition or as a resistance to those discourses as forms of health citizenship. However, the thesis chapters illustrate that the movement away from the clinic and its accompanying normative subjectivity- the healthy citizen- is not a direct or clear-cut path. The chapter structure also reflects some of the defining and innovative characteristics of the ADAO as an organization and the practices of resistance it has incorporated into its organization and communities. Ultimately the thesis poses the question of whether the ADAO constitutes a new kind of space or alternative within the wider landscapes of anxiety service provision? And whether this is desirable or achievable for the ADAO in the first place?

The tension between these two sections involves analyzing how the ADAO's discourses and spaces negotiate, adopt or resist discourses, beliefs and spaces within wider clinical care system in which it is situated. These issues are not only relevant to the maintenance and growth of the ADAO they are also connected to the kind of society and political community the ADAO desires which is intimately connected to the way that citizenship is defined and understood (Mouffe, 1992:225 in Young, 2000). What underpins the thesis chapters is a movement from thinking about the healthy citizen, who develops a sense of self and self worth through specific beliefs about the body, the importance of the expertise and authority of the 'clinic', towards the development of health citizenship where the embodied geographies of citizenship and forms of expertise that draw upon the voices of sufferers themselves are central. Ultimately does the ADAO create a space in which the diverse experiences of individuals affected by panic are responded to, and seen as important in the context of the political?

The thesis concludes with chapter nine which draws together themes within the thesis chapters around the issue of health citizenship in order to reflect on the tension between the ADAO's desire to network with other institutions and groups while simultaneously maintaining its own visions. This conclusion restates the diverse theoretical themes that have bridged the thesis chapters together and highlights insights made about the role of the ADAO in the context of enhancing identity, community and subjectivity. The thesis' findings are not only of potential significance for sufferers of anxiety conditions and sufferer led anxiety groups, but they offer a significant contribution to feminist,

geographical and political understandings about the relational nature between self and subject, self and other, and self and space. The conclusion highlights ways in which the thesis has contributed to the production of geographical, political, and feminist knowledge and theory. The conclusion primarily focuses on some of the contributions the research has made for the production of geographical knowledge.

Chapter Two - Literature review

2.1 Introduction

This chapter reviews various bodies of literature of relevance to anxiety service provision. These literatures help structure themes and issues central to the thesis as a whole. Some themes are present throughout the research process, i.e. subjectivity, disability and embodiment while others emerge as a result of the research process itself, i.e. health citizenship. The wide range of literatures used within this chapter reflects the wider interdisciplinary framework of the thesis as a whole. Bringing together work from feminism, sociology, cultural studies, architecture, geography and political theory should help the reader position himself/herself relative to the interdisciplinary approach of the thesis. The chapter bridges this range of literatures relevant to anxiety service provision within a geographical framework, which helps to highlight the thesis's place within geography. Additionally because feminist scholarship has informed the thesis as a whole, this chapter also draws attention to the place of the thesis relative to feminist theory.

Because this thesis revolves around the case study of the ADAO, this chapter expands on material that helps the reader understand more about issues pertinent to anxiety service provision. Thus, the chapter begins with a discussion about anxiety conditions themselves. Section 2.2, explores meanings and understandings of anxiety with particular reference to agoraphobia. Focusing on agoraphobia is illustrative of my particular research interests, representative of the majority of interviewees' experiences with anxiety conditions, and characteristic of the original focus of the ADAO. Conventional and dominant discussions about anxiety conditions are based on clinical discourses and etiology that serve to reify clinical knowledges (Antony and Swinson, 1996; APA, 2000; McNally, 1994; NIMH, 2003; Walker et al., 1991). However, the literature reviewed within this chapter focuses on discourses on agoraphobia within the social sciences and humanities. This is appropriate because this thesis is located within, and informed by, those discourses. Additionally, this chapter brings together a wide range of non-clinical literatures on anxiety and agoraphobia in particular, which is unique in the clinical and non-clinical literature on the subject. The material in this section is particularly useful in reference to chapter five, where more detail about the experience of panic and agoraphobia is analyzed.

The review continues in section 2.3 with a discussion about anxiety health service provision with specific reference to the geographical literatures on mental health. The section examines the geographical literature on mental health with a particular emphasis on the role of care within those geographical discourses. A focus on geographical writings, not only highlights the place of the thesis in the context of geography, but also the importance of space and place in relation to mental health, which is a central theme found throughout the thesis. The geographical literature contains important insights about the individual experiences of mental health alongside insights about health service provision. The review of geographical literatures brings a focus to the spatial aspects of service provision and mental health, which is also largely absent within the wider literature on anxiety conditions.

The next and final review section, section 2.4, elaborates on other themes central to the thesis: the production of health citizenship; and the connection between anxiety service provision and concepts of subjectivity. Section 2.4 uses feminist political theory to develop the geographical insights on mental health within section 2.3 with issues that concern health citizenship. In this way the section addresses questions about political and collective responses to anxiety conditions in the form of anxiety service provision. Specifically the section focuses on concepts of care and autonomy, as these are issues central to citizenship, mental health, and feminist and geographical scholarship more broadly. Care and autonomy are intimately connected to the rhetoric and practice of health, and thus need to be unpacked and analyzed. They act as wider frameworks that affect the process of providing and determining what is and is not appropriate health service provision, thus, they are significant for processes of subjectivity. Care and autonomy are also themes in themselves found within the substantive arguments of the thesis. Autonomy is a central issue in chapter seven, however, the review of autonomy in this chapter is much more broad in scope and helps to frame the discussion of relational autonomy in chapter seven. Additionally, section 2.4 provides more room for discussion of care than is done in chapters five through eight. This should help the reader situate and complicate the material on care in the following chapters.

2.2 Meanings of anxiety: beyond clinical accounts

2.2.1 Constructions of anxiety

The ADAO deals with what the DSM identifies as anxiety disorders. This includes a wide range of conditions such as: panic; panic with agoraphobia; persistent obsessions and compulsion; generalized anxiety; post traumatic stress; social phobia; and specific phobia (ADAO, 2002). While the DSM refers to these conditions, as ‘disorders’ the ADAO does not, as the labeling of anything as diseased or disordered is stigmatizing (see also Kirk and Kutchins, *The selling of the DSM- the rhetoric of science in psychiatry* (1992). They prefer the use of the term condition, a term I use frequently to replace disorder, except when I am emphasizing or discussing aspects of the ‘clinic’ or when I am trying to emphasize the voice of the ‘clinic’ within the thesis material.

Currently anxiety disorders include the general categories of panic disorder (with or without agoraphobia), agoraphobia without panic disorder, social phobia, simple phobia, obsessive compulsive disorder, generalized anxiety disorder, and post traumatic stress disorder (APA, 2000). Within the history of the DSM the categorization of anxiety has shifted and expanded over time. This shift in diagnostic categories of anxiety, though well documented and discussed within clinical literatures, has not by and large been of interest to those in the social sciences. However, there is an expansive literature on anxiety within the social sciences that reflects a growing preoccupation with understanding the inner self and the self’s ability to cope with mental and emotional distresses of modern life (Wilkinson, 2001). Wilkinson cites a long list of influential thinkers who have discussed the notion of anxiety within their work: Marx (1845), Freud (1929), Horney (1937), Fromm (1942), Auden (1948), Weber (1949), Simmel (1950), Durkheim (1964), May (1977), Giddens (1991), Douglas (1992), Beck (1992), Bauman (1993), and Lupton (1999) (for references see Wilkinson, 2001). Within the social sciences ‘anxiety’ is understood and discussed as an example of: a physically debilitating problem; a problem of ‘personality’ and self definition; an existential condition; a symbolic trope and form of culture: an affect of our knowledge and society; a cultural narrative of late modernity; and a marker of how something is seriously wrong with the conditions of our social world. There is no consensus as to what the definition of anxiety is, or what feelings constitute anxiety, and as such the term is used nebulously and interchangeably within the literature (Rachman, 1998). Even within the DSM and amongst practitioners, clinicians apply their

own rules about the meaning of anxiety thus the reading of anxiety, as a clinical diagnosis, is often considered variable and unreliable (Andrews and Peters, 1999).

Traditionally anxiety conditions, notably panic, have been viewed as a problem of self-definition in both clinical and non-clinical literatures. In clinical literatures anxiety and anxiety conditions are:

“The result of a faulty process of reasoning which leads an individual to overestimate the reality of a prospective danger and underestimate their capacity to keep themselves from harm’s way. Having identified the cognitive errors that cause them to misapprehend reality of their circumstances, the aim is to introduce them to alternative frameworks of understanding use to construct new relational meaning towards the problems that place them in distress” (Wilkinson, 2001:71).

In clinical discourses anxiety, and similarly panic, are products of the interrelationship between affective experiences, personal histories, emotional characteristics, bodily reactions and behavioral responses (Wilkinson, 2001:15). Thus, anxiety and panic are conceived of as individualistic problems reflected in the way clinical research has primarily focused on individual therapy (Rachman, 1998). Cultural components of anxiety or panic are of marginal concern as clinicians are more concerned to help their patients come to a new way of seeing their experience of the world and themselves so that their problems do not appear as great as to prevent them from living a ‘normal’ life (Smail, 1998; Wilkinson, 2001:16). Thus clinical experts teach sufferers styles of thinking and behavior that will enable them to exercise more control over their symptoms of distress (Hallam, 1994 in Wilkinson, 2001:70). In this way the explanation, measurement and treatment of anxiety ‘disorders’ often has little to do with the relationship between anxiety, culture, and meaning and is more closely connected to psycho-physiological distress.

Within the social sciences the problem of anxiety is contextualised within the struggle for self-definition and search for meaning. Thus rather than seeing anxiety as a burden it can become an opportunity for higher meaning (Wilkinson, 2001:65). Wilkinson describes how for Kierkegaard (1980) anxiety is a source of spiritual education while for May (1977) it is a source of creativity and invention. The problem of anxiety lies in the fact that it appears to be directed towards nothing (Kierkegaard, 1980:43 in Wilkinson, 2001:20), that the focus of fear in anxiety is elusive (Rachman, 1998) or as Rollo May (1977), following Freud, remarks, anxiety has an objectless nature: “as the security base

from which the individual has been able to experience himself [sic] in relation to objects, the distinction between subject and object also breaks down" (May, 1977:208). Anxiety is viewed as a barrier to self realization, where the individual feels as if s/he is being denied the fulfillment of her/his ambitions and the development of her/his individual potentialities (Wilkinson, 2001:31). Similarly if anxiety is seen to be central to the development of the self, then it is assumed that those who are best able to cope with their anxieties are more able to possess a sense of coherence that promotes self confidence and the belief that one is in control over one's life, and those who are less able to control their anxiety are more prone to insecurity and abnormality (Wilkinson, 2001:68). Anxiety becomes poised against ideal types of normative and social character. It is complicated by the myth of individualism in which individual strength of will is central to overcoming all problems (Smail, 1999 in Wilkinson, 2001:80).

According to Wilkinson, the social sciences did not devote explicit attention to the problem of anxiety until the 1930's. Sociologists who were interested in the association between social and cultural processes and high states of anxiety as a normal occurrence of everyday life (Glaser, 2003). More recently however anxiety has become a central metaphor for the discussion of the risk society (Beck, 1992; Giddens, 1991) and risk consciousness (Lupton, 1999a; 1999b), where knowledge and fear of risk is the major cause of anxiety. For Wilkinson anxiety should be seen not only as an individual phenomenon but also as a reaction to social processes and cultural experiences that act as a threat to our personal security and our identities (Wilkinson, 2001:9). Being vulnerable to anxiety is not conceived of as a consequence of individuals having something wrong with them, but as a result of social antagonisms, cultural myths and the imagined geographies of threatening uncertainty (Glaser, 2003:30). Anxiety is determined by social opportunities, and cultural resources that help create purpose and meaning in our lives (Wilkinson, 2001:88). For example, Wilkinson also notes that viewing anxiety as distress is contingent on people defining and describing their experiences as distressful. Thus, while oppressive socialization may place individuals in risky, disadvantaged situations, individuals may become resigned to their 'place' in life, thus may not feel distressed or anxious. Wilkinson attributes the decline in community and 'tradition' and the increase in the need for individualization as central to the development of an environment in which we are vulnerable to anxiety. Ultimately anxiety for Wilkinson highlights how consciousness is also a problem of culture, as expressions of behavior are given meaning

through symbolic forms of culture as well as the experiential content of values and beliefs which give meaning to their existence (Wilkinson, 2001:47).

2.2.2 Focusing on agoraphobia.

The majority of individuals that come to the ADAO for assistance or advice have panic and agoraphobia. In fact, the ADAO was originally the Agoraphobia and Peer Volunteer Association (APVA). The APVA/ADAO was formed as a need to address the problems faced by individuals with panic and agoraphobia and it has expanded since then. Panic and agoraphobia are also experiences that most of those interviewed had experienced or focused on as central to ADAO service provision. Thus, further understanding agoraphobia and the wider literatures that surround it are central for the thesis. In this section I use the term agoraphobia as shorthand to refer to the experience of panic and agoraphobia. Most people within the ADAO, who identify as agoraphobic, connect their mobility impairment to the experience of panic, which will be further discussed in chapter five. I also use the term agoraphobia because much of the literature on agoraphobia does not address the relationship between panic and agoraphobic avoidance behaviours, thus the term is consistent with its use in those texts. I begin this section with an overview of writings on agoraphobia. I then draw on the writings on agoraphobia of Reuter, Callard and Davidson. Each of these authors employ very different approaches to the subject matter, however their writings expand on issues and themes discussed within the thesis. As geographers, Callard's and Davidson's work are important in the context of this thesis, while Reuter is a sociologist whose Foucauldian approach provides different but interconnected insights on agoraphobia that are further developed within chapter six of the thesis.

2.2.3 The metaphor of agoraphobia

Most writings on agoraphobia identify a similar historical trajectory of agoraphobia beginning with the creation of a diagnostic category. Carl Otto Westphal's article *die agoraphobie* (1872) is often regarded as the starting point for the history of agoraphobia and modern literature on phobias. Westphal described agoraphobia as *platzschwindel*, defined as dizziness upon entering particular places. It is from this point onwards that discourses and literatures on agoraphobia have developed a life of their own. This literature has continued to grow in the humanities and social sciences. However the

understanding and meanings of agoraphobia are often varied within these literatures. The vast majority of writings in the social sciences and humanities on agoraphobia use agoraphobia as a platform, 'structure of signification', or metaphor from which to discuss and examine a wide range of social, cultural, philosophical, gendered and geographical issues. These writings tend to rely on the connection between agora and agoraphobia, thus they invoke a definition of agoraphobia as rooted in the spaces of the ancient Greek agora- whether they be open spaces, public spaces, meeting spaces or market places. This literature also tends to rely on existing literature on agoraphobia, much of which is based on a limited number of older clinical studies (For example Brehony, 1983; Chambless and Goldstein, 1992; Chambless and Malson, 1986; Deutsch, 1929; Symonds, 1973). What is problematic about the literature is that often the authors of these writings do not seem aware that the definitions they employ of agoraphobia do not always connect with the experience of sufferers who identify themselves as agoraphobic and their experiences of panic. There is a smaller literature on agoraphobia that is concerned to bring to the fore the daily lived experiences and definitions of agoraphobia of sufferers themselves (For example Bankey, 2002; Bordo, Klein and Silverman, 1998; Davidson, 2003; Capps and Ochs, 1995; Garbowsky, 1989; Gardener, 1995). This literature complicates a definition of agoraphobia as rooted in the agora, as agoraphobia becomes a more complex interaction between body and environment, that may or may not have anything to do with open, public or market places. It is a literature motivated both by the inaccuracies in clinical and non clinical literatures of agoraphobia and a desire to show how the first hand experiences of those who consider themselves to be agoraphobic provide important insights for other study.

It is important to understand agoraphobia as part of a spectrum or continuum of experiences that connect our anxieties and fears to the external worlds in which we live. Taken together these literatures are dialogic; they speak to each other in ways that help potentially inform the other. Emphasizing and exploring the connectedness of various agoraphobic discourses helps to show the different critical possibilities between them, and the varied gaps which need to be addressed. Differing understandings of agoraphobia help further define the spectrum or continuum of 'Agoraphobia' as part of the human condition, as something experienced by many different people at different times, as part of a broader western tradition/condition, and as specific accounts of the actual lived and embodied experiences of those with panic and agoraphobia. Understanding agoraphobia in its different forms opens up venues for analysis and discussion where agoraphobia is

not just pathology, but also a complex combination of social, spatial and gendered practices. As da Costa Meyer explains “we must historicize and contextualize agoraphobia, not just pathologize it”(da Costa Meyer, 1996:149).

Paul Carter’s text *Repressed Spaces: The Poetics of Agoraphobia* (2002) is concerned to explore the connection between the agora and agoraphobia. Carter draws upon a number of agoraphobia metaphors found within the wider literature. For example, metaphors of agoraphobia include: an example of the pathologization of culture and an example of the operation of the clinic (Reuter, 2002); a metaphor for alienation within the city (Callard, 2003b; da Costa Meyer, 1996; Vidler, 1993); a metaphor for the fragmentation of social life under late capitalism (Carter, 2002); a metaphor for the logic of modern urbanism and its mythology of progress as movement (Callard, 2003b; Deutsche, 1996; Vidler, 1993); a metaphor for our malaise with urban modernism ‘divorced from moral value, bland and soulless’(Carter, 2002); a metaphor for the fear of engaging oneself in the political life of the public sphere and its communities (Deutsche, 1996); and the metaphor of agoraphobia as a reaction to the social, economic and gendered construction of women under patriarchy (da Costa Meyer, 1996). Carter uses these metaphors to help elaborate on his own project that utilizes agoraphobia as an example of how external ‘space’ has been repressed or ignored within psychoanalytic thought, specifically Freud’s own work on the self, which has come to influence meanings and perceptions of agoraphobia. Thus for Carter agoraphobia becomes a metaphor for the failure of psychoanalytic thought to come to terms with its own environmental neurosis, a metaphor for the failings of modern urban life, as well as, a metaphor for the repressed space of human relations (Carter, 2002: 158).

In the literature that is concerned to explore the daily-lived conditions of agoraphobics, for example Joyce Davidson’s text *Phobic Geographies: The Phenomenology and Spatiality of Identity* (2003) metaphors of agoraphobia are also employed. Agoraphobia becomes a metaphor within these literatures for: twentieth century constructions of femininity (Bordo, 1988; 1993); gendered geographies, which have arisen and developed as a result of cultural sex role stereotypes or the feminization of women (da Costa Meyer, 1996; Gardener, 1994); a spatial expression of the restricted economic geographies that women are consigned to within a patriarchal structure (Brown, 1987); a metaphor for resistance and a way in which women can subvert western consumerist societies (Gardener, 1995); a virtual parody of twentieth- century constructions of femininity, based on a literal interpretation of domesticity as immobility, helplessness and

infantilisation (da Costa Meyer, 1996); a metaphor for the conflicting relationship between western society, sexuality and intimacy (deSwaan, 1981); a metaphor for woman as symbolic capital enmeshed in the regulation of women according to restrictive, immobilizing social and sexual norms (Brown, 1987; deSwaan, 1981); a metaphor for the historical spatialization of patriarchy and the creation of separate spheres as well as issues of public harassment, assault and public safety (Bankey, 2002; Callard, 2003b; Gardener, 1995); and as a metaphor for the consequences of the socialization of spatial fears on our bodies, identities and subjectivities (Bankey, 2001, Bordo, 1993; Bordo, Klein and Silverman, 1998; Gardener, 1995).

2.2.3 Agoraphobia and the discursive

Shelley Reuter's work on agoraphobia (2002) helps build on arguments on processes of governmentality, expertise and a self care ethic discussed within chapter six of the thesis. Reuter's sociological and historical work on agoraphobia explores the modern literature on agoraphobia from the nineteenth century onward. Her argument in this work is to analyze the disease category of agoraphobia in terms of the socio-cultural process of embodiment that unfolds in and through (disease) categories (Reuter, 2002:751).

Reuter highlights, following Foucault, how the diseased body has been transformed into a discursive site as both object and subject of study. The body is both the object of medical knowledge, the clinic, as the living embodied fleshy bodies that are our modes of living (Mol and Law, 1999 in Reuter, 2002:752). Agoraphobic practices are for Reuter examples of "the operation of the clinic and the principle of its entire discourse" whereby, through practices of objectification, patients are transformed into subjects of medicine (Foucault, 1973:xviii in Reuter, 2002:754). This process is one based in binary relations, healthy-sick, sane-insane, normal-pathological, a process in which persons then turn themselves into subjects, because they recognize themselves as subjects (Foucault, 1982:208 in Reuter, 2002:1978). For Reuter agoraphobic bodies have been positioned as docile subject-objects of the "psychiatric order" yet, for her, this fails to account for the diverse agoraphobic bodies that emerge in defiance of diagnostic norms intended to constrain them (Reuter, 2002:754). According to Reuter resistance is conceptualized as variability of meaning rewritten as doctors' notes. She argues that a singular discourse on agoraphobia generated by physicians who wrote case reports, invoked by disease theories and case histories, helps to enact the agoraphobic body through discourse (Reuter,

2002:755). These discourses were both gendered and moralized. Before WW1 most patients diagnosed with agoraphobia were male. After WW1 women were more predominantly diagnosed. By examining, measuring, testing and listening to their patients talk about their experiences doctors also enact agoraphobia. They do so through writing the disease in the form of articles. In this way “medical literature mediates the relations that it organizes [and] the bodies that are configured through it” (Berg and Bowker 1997:514 in Reuter, 2002:761).

Agoraphobia is performed. The materiality of agoraphobic bodies is constituted in and through disease categories that are normative and regulative. This has implications for agoraphobic bodies because according to Reuter they are unintelligible outside these meaning structures (Reuter, 2002:764) In other words:

“[T]he body is not merely where a disease happens but it is also the material discursive instantiation of a deeply social contestation: the theories of disease and the ideas about culture and the social that are invoked in writings about agoraphobia amount to the deployment of discursive structures of abjection that regulate the material intelligibility of this disease” (Reuter, 2002:765).

Shelley Reuter’s work has much to offer in terms of thinking about the way in which agoraphobia is both performative and socio-medically constructed. But her work is also problematic because the textual worlds from which she studies and works are not the only ones that come to provide meaning in the context of agoraphobia. Her discussion of the “body as an intra-action between the material and the discursive - that bodies are something we do, we enact” is then extended into the statement that “practices related to agoraphobic bodies are only rendered intelligible and relevant through the expression of this disease category in language”, by which she means written language (Reuter, 2002: 752). The work of various geographers suggests that while the written histories of agoraphobia help to shape its expression, meanings and beliefs about agoraphobia are also shaped by the history of spatial forms and visual imagery, as well as by particular life experiences which may never be relayed to a clinical professional (Bankey, 2002; 2004; Davidson, 2000a). Additionally by stating that agoraphobic bodies are only rendered intelligible through language limits the scope and place in which meaning is created to the spaces of the clinician’s office.

In this way, Felicity Callard’s work on agoraphobia, which is also textually and historically based, offers an analysis of the literature on agoraphobia that Reuter does not.

Callards' work on agoraphobia (2003a; 2003b) is a historical account and literature review of agoraphobia with a particular focus on the relationship between mental health and the built environment:

“As I hope to demonstrate, visions of the built environment, public space and the individual have important ramifications for understandings of intervention and cure. In the process, therefore, those visions carry implications for the practice of mental health promotion”(Callard, 2003b).

Similar to da Costa Meyer (1997), she analyses discourses on urban design and its relation to the etiology of agoraphobia. Agoraphobia, according to Callard was, from the moment of its emergence as a named disorder, fundamentally connected to debates about the metropolis and our vision of the city (Callard, 2003b; Vidler, 1993). Just as the city has changed within the past century so have meanings of agoraphobia. For Callard agoraphobia may be understood as a product of the individual self (the physical body, the unconscious), the social world (socio-cultural and gendered norms), and within “space”, as a condition of our built environments, where the self, social and spatial are interconnected (Callard, 2003b). While Callard's work seems to be genuinely concerned with understanding agoraphobia, its basis within a literature that has historically rewritten and excluded the voices and experiences of those who are agoraphobic highlights that there are still gaps that need to be addressed.

2.2.4 “Life-worlds” of agoraphobia

Davidson's work represents a departure from that tradition of writing ‘about agoraphobia’ within the social sciences towards a lived and first hand account and analysis of the meanings and experience of agoraphobia (see also Bankey, 2001; Bordo, Klein and Silverman, 1998; Capps and Ochs, 1992).

Within geography, Joyce Davidson's work involves the most comprehensive and detailed discussion of agoraphobia. In fact it is one of the most thorough examinations of the daily-lived realities of agoraphobia within the social sciences. Davidson's work shares many similarities with work in this thesis, in terms of an interest in exploring aspects of agoraphobia that have previously been silenced or unheard, as well as, a concern with the experiential realities of daily life for agoraphobic individuals. Her work seeks to readdress the lack of attention given to agoraphobia outside of medical, psychiatric and

psychological contexts. Yet, the material that Davidson uses to further an understanding of agoraphobia is different from the material that I have used (Bankey, 1999; 2001; 2002; 2004). Her work covers a variety of subject matters and is fundamentally concerned to discover how feminist geography, feminist philosophy and phenomenology helps to further an understanding of the experiential dimension of agoraphobia - its "life worlds" (Davidson, 2000b:31). She is also concerned to articulate the fundamentally "*spatialized nature of agoraphobia*" (original emphasis, Davidson, 2001a:214). In her work she is critical of the existing clinical and non clinical literature on agoraphobia arguing that the experience of agoraphobia is often not talked about in terms of its spatial and embodied disruptions, and as such should be conceived of as a "boundary crisis" involving panic (Davidson, 2002; 2003). She argues that the definition of agoraphobia as a fear of open spaces is a misconception based on a general lack of information about agoraphobia, and that it is peopled or public spaces that are more often feared (Davidson, 2001a; 2001c; 2002). Davidson highlights how the traditional meaning of agoraphobia as fear of the marketplace, is both an interesting and relevant explanation of the experience of agoraphobic women, as a fear of spaces of consumption, in particular the shopping mall, is prevalent amongst those she researched.

In her book *Phobic Geographies* (2003) Davidson compiles her articles on agoraphobia published elsewhere. In the book we see how the corpus of her work focuses on the high incidence of women diagnosed with agoraphobia. She not only focuses of the effects of pathologizing agoraphobia, being 'all in the mind', but the effects of feminizing fear and its ramifications for agoraphobic women (Davidson, 2003:131). Her theoretical inquiries into agoraphobia are not separate or removed from the everyday life of agoraphobics, as questions of identity, subjectivity and being are always embodied and placed (Davidson, 2003:143). She emphasizes how the sensations of panic come to affect the mapping of agoraphobic spaces within and outside of the body, and how these spaces are co-constitutive. Her work centers on a questioning of the boundaries of agoraphobia (Davidson, 2003:144). She is particularly interested to add a phenomenological dimension to an understanding of panic as a form of existential angst, as a threat to our sense of self and the dissolution of the self that brings to the fore questions of identity (Davidson, 2003:141). Her focus on sufferers themselves results in a concrete exploration of the spaces and experiences of those who identify as agoraphobic. These spaces include therapeutic spaces such as self help groups, and the particular and individualistic agoraphobic geographies or life worlds of agoraphobics, typified for example by the

experience and geographies of shopping. She highlights how many of the spaces avoided by those who are agoraphobic are connected to gender roles and the spatialization of patriarchy. However she also highlights that fundamentally agoraphobic avoidance behaviors are a product of a fear of having a panic attack, and a fear of being seen in a state of panic, thus agoraphobes tend to fear 'peopled' or social space rather than open spaces (Davidson, 2003:121). Davidson is primarily interested in the importance of listening to, rather than writing about the embodied and daily spatial experiences of those who are agoraphobic (Davidson, 2003:144). Ultimately her work is directed not just at those who identify as agoraphobic, but for feminist therapists and theorists more broadly (Davidson, 2003:144).

Davidson sees clinical discourses on agoraphobia, and the therapies derived from those discourses, as based within a Cartesian mind/body dualism that is masculinist. Some of her work focuses on the subject of coping; particularly through the use of self help groups. When she talks about the subject of self-help and "self help", she refers primarily to texts and processes that are expert and clinically directed, in particular cognitive behavioral therapies (2002:30). Thus self help is not seen as separate from clinical practice but constitutive of it, a position that many clinicians (and some social scientists see Rimke, 2000; Scott, 1999; Wiles and Rosenberg, 2001) would argue against. For Davidson:

"The term self help can either be read in the (common) sense of "help your self", or in the alternative more complex sense of "help for the self". The difference here lies in what is straightforwardly self-service, and what is a kind of therapy for the treatment of selves. Both senses clearly harbor implicit definitions, but the latter begs specific questions regarding the nature of assumptions underlying this definition. Given that there are contested notions of what a self is or can be, whose idea of self is being invoked here? To exactly what kind of self is help being offered" (Davidson, 2002:16).

What she then argues is that it is a masculinist Cartesian version of the self, divided into mind (*res cognitae*) and body (*res extensa*), where mind is privileged over body that informs the self-help resources she analyzes. Thus the agoraphobic self is pitted against and dependent on a normal (masculine) identity (Davidson, 2002:16). Yet, agoraphobic individuals may never feel that the contained boundaries of self and space are isolated from one another. She further goes on to explain how this Cartesian self is bound within a moral self, where "deviations from normal behavior for which no somatic explanation is provided inevitably carry a social penalty, since psychological problems are considered

less 'real' and more blameworthy than physical defects" (Yardley, 1997:115 in Davidson, 2002:25). Because of this Davidson argues in it is in the interest of agoraphobic individuals to present their 'disorder' as physiological, within the realm of rational (masculine) biological medical discourse and to describe fear as a feminine attribute (Davidson, 2002:25). However, she also argues that in fact the manner in which sufferers represent and describe their experiences pose a challenge to Cartesian rational discourses. As a result Cartesian conceptualizations of subjectivity are not adequate in articulating and explaining agoraphobia, and that the artificial division between somatic and psychic functions results in important aspects of agoraphobic experience untreated and unexplained (Yardley, 1997:114 in Davidson, 2002:30). Within her research she has found that while there are a variety of differences in why people become agoraphobic, and who is agoraphobic, subjects of her research seem to have significant overlaps in the spatial and temporal phenomenology of their experiences of agoraphobia (Davidson, 2001a).

Agoraphobia, for Davidson, is seen to result in a gendered geography of exclusion that is spatially mediated and constructed. As is discussed in chapter five of the thesis, the inability to locate the source of fear that triggers panic attacks and results in agoraphobic avoidance behaviors results in the breakdown of the boundaries between self and space, person and place (Davidson, 2000b; 2001c). The experience of agoraphobia threatens a dissolution of the self, where the boundaries between what is inside and outside of the body become confused and distorted (see also Bordo, Klein and Silverman, 1998). This results in a loss of trust in the stability of our bodies, a loss assumed to be visible to others.

2.2.5 Addressing gaps

As developed within section 2.2, the variety of work on agoraphobia all has something to offer one another. This section brings together material on agoraphobia and anxiety conditions that have not been brought together or written about elsewhere in the literature. The discussion of agoraphobia as metaphoric is unique and innovative. The section has shown that agoraphobia, along with other anxiety conditions, could be understood as a part of the human condition. This 'agoraphobic condition' should be viewed as a spectrum of experiences that range from sufferers' first hand experiences of panic to a

broader experience of western culture. This helps to create an understanding of agoraphobia that is multifaceted and complex. The work on anxiety conditions and agoraphobia within this thesis builds on these authors' contributions and addresses a variety of gaps within existing literatures. First, there is little discussion about the role of organizations that address anxiety conditions within both clinical and non-clinical literatures. Second, there is also little discussion about issues of citizenship and community with reference to the experience either of sufferers themselves or the groups that assist those individuals. Third, analysis of the dilemmas around collective organizing and anxiety conditions is absent in the literature. And fourth, this thesis brings together literatures from feminist, geographical, architectural, sociological and cultural studies for the first time in the context of the study of agoraphobia or anxiety conditions.

2.3 Understanding anxiety health service provision

2.3.1 Introduction

The next two sections of the chapter, 2.3.2 and 2.3.3, address a lack of writings within both clinical and non-clinical literatures on the work done by non-clinical anxiety service providers. This is done in order to further understand one of the central themes of the thesis - the tensions experienced by the ADAO in trying to negotiate a place for itself within the wider 'health care' system and the importance of health citizenship for that reconciliation. The literature review focuses on two aspects of this question/tension:

- 1) The importance of geographical perspectives on mental health that further an analysis of how landscapes of care, that affect the form and content of anxiety service provision, are (re)created and (re)produced.
- 2) The ways in which contested meanings of 'care' and 'autonomy' affect the development of a 'health care' system. This further informs the reasons behind tensions within and amongst anxiety service providers, as well as the ways in which 'health care' is directly tied to models of the healthy citizen and health citizenship.

Section 2.3.2 turns to 'post-medical mental health geographies' to help us think about how to approach anxiety service provision (Parr, 1998b). Post-medical mental health geographies refers to a "second wave" of mental health geographical work, since the 80's, that is rooted in social theory, utilizes mostly qualitative methods, and has focused on the

social construction of difference (Wolch and Philo, 2000:138). Post-medical geographies bring together a range of interdisciplinary work on mental health that is in keeping with the interdisciplinary framework of this thesis as a whole. This section also highlights the centrality of geographical work for addressing questions about anxiety service provision that are developed within the substantive chapters of the thesis.

Section 2.3.3 turns to work within feminist political theory to think about the how contested meanings of care and autonomy help create discursive meanings of 'health care', that inform the appropriateness of anxiety service provision. This section specifically elaborates on meanings of care and autonomy that are employed by the ADAO conducive to the development of health citizenship. The ADAO's positioning of care and autonomy helps create a space that is different from other anxiety service providers within Ottawa and across Canada, thus the way in which the ADAO refigures care and autonomy within its programs, structure and mandate offers a direction to the question the tension of how to create a space of its own connected to the wider context of anxiety service provision. The material in this section provides a contrast to discussions and meanings of 'autonomy' and 'care' that are based in the relationship between self and subject, that is governing and caring for the self through specific imperatives of health, described in this thesis as central to the healthy citizen (Lupton, 1995). For example, meanings of 'autonomy' centered on self-surveillance of the body, and creation of bodily and intersubjective boundaries found in chapter five, and meanings of 'care' centered around modes of governmentality and 'self-care' that structure the argument of chapter six. Simultaneously, the material in this section provides a foundation for discussions around autonomy in chapter seven, and discussions on community and health citizenship in chapter eight that are based upon discursive meanings of 'care' and 'autonomy'. 'Health care' in this way is more concerned about the relationship between self and other and the interpersonal, which is tied to the creation of boundaries between self-subject, internal-external, and self-space

Taken together these two sections, 2.3.2 and 2.3.3, problematize taken for granted assumptions about care and autonomy present in models of health citizenship and the healthy citizen. It is these assumptions that contribute to an understanding that the ADAO's tensions around networking are directly connected to differing perspectives on care and autonomy, a theme that is elaborated on throughout the substantive chapters of the thesis.

2.3.2 Geographies of anxiety service provision

2.3.2.1 Post-medical mental health geographies

Because the discussions around health citizenship in this thesis highlight the fundamentally embodied and spatial nature of subjectivity, it is important to draw on literatures that explore the connections between embodiment, health, identity and subjectivity. Geographers have become increasingly interested in the lived realities and theoretical debates surrounding ill and impaired bodies, and how these geographies draw attention to how complex power relations are spatialised (Butler and Parr, 1999). Post-medical mental health geography focuses on the relationship between mental 'illness' and relations of space and place, in which the experience of anxiety conditions such as panic and agoraphobia should be included. Post-medical mental health geographers, like health geographers more broadly, draw upon a wide range of interdisciplinary writings and studies in order to explore the interconnections between mental health and wider socio-cultural, gendered, economic, political, somatic and medical environments. Much of the attempt in geographical disciplines to connect social, clinical, and political issues to one another has been to destabilize a limiting mind-body dualism in human geography that reinforces the disciplinary boundaries of what can and cannot be studied within a geographical context (Butler and Parr, 1999). However unlike many health geographers post-medical mental health geographers also highlight the intersection between ablesim, illness and topographies of fear that are essential to understanding the experiences of those with anxiety conditions (see Parr, 1999b; 2000). Ableism refers to "ideas, practices, institutions and institutions that presume ablebodiedness, and by so doing, construct persons with disabilities are marginalized, oppressed and largely invisible others" (Chouinard, 1997:380). By exploring how the diverse geographies of illness/ impairment/ disability are related to the geography of women's and men's fears, mental health geographers draw attention to different embodied experiences and the complex interconnections between mobility, identity, subjectivity and wider clinical environments (Butler and Parr, 1999; Tuan, 1979).

Various health geographers have identified how medical geography has historically fallen into two camps: positivistic/behaviouralist, and more recently post-positivistic (post-medical) work which includes a number of different perspectives from social theory (Wolch and Philo: 2000). Positivistic/behaviouralist work is more concerned with models

of health and disability that have focused on clinical science and place emphasis on medical facts, structures, diagnosis, etiology, outcomes and treatments. Post-positivistic geographers are more concerned with social models of health and disability that shift away the focus from physiology to a more critical investigation of the contexts in which ableist identities, subjectivities and lived experiences are produced (Dear et al., 1997; Dorn and Laws, 1994; Dorn 1998; Grant and Chouinard, 1995; Moss and Dyck 1997; 1999a; 1999b). These geographers are concerned with the re-theorization of place-based understandings of health in medical geography as complex, material, sociological, experiential and philosophical phenomenon and how this is crucial to rethinking through how the local is involved in the making of and experience of different mind and body states (Butler and Parr, 1999:11). Social models of health and disability critically examine the social categorization of illness, disorder and disability as well as the complexity of lived reality of those within systems of health practices (Butler and Bowlby, 1997; Cormode, 1997; Hall, 2000; Imrie, 1996). Health is not simply seen as a matter of physiology but a condition involving human rights that politicize spatial-making practices and spaces themselves (Chouinard and Cormode, 1997; Doel and Segrott, 2003).

The geography of mental health is often situated within post-positivistic (post-medical) models of health and involves a much closer association between social and clinical practices (Parr, 1998a; 2002b; Parr and Philo, 1995; Philo, 1995; 1997). These discussions not only question the dualisms of mind/ body but of the production of otherness vis à vis normal/abnormal, sane/insane dualisms, and how these dualisms have problematically normalized various medical practices, processes of abjection and the manufacture of the 'ableist gaze' (Dear et al., 1997; Nast and Pile, 1998; Sibley, 1995). This literature also explores the how mental illness is far less desirable and acceptable than physical illness (Milligan, 1999). In these ways disability/illness/disorder becomes a socially constructed boundary marker that fuels and informs exclusionary actions from the everyday spaces of public and private spheres (Butler and Parr, 1999).

Mental health issues have been explored in a variety of ways within mental health geography that range from the embodied, personal and individual to the collective and historical (Wilson, 2003). These discourses include discussions of the experience of sufferers and their families themselves (Butler and Bowlby, 1997; Parr, 1997; 1999b); the experience of practitioners and the practice of providing mental health (Bondi, 2001;

2003; Brown, 2003); the history of mental health with a particular focus on the development of places of mental health (Gleeson, 1999; Gleeson and Kearns, 2000; Milligan, 1999; Parr, 2000; Takahashi, 2000); notably institutions and asylums (Philo, 1995); the legacy and history of mental health relative to the creation of meanings of madness and the mental (Creswell, 1996; Parr, 1999a; 2000; Philo; 1995; 1997) and the ways in which mental health issues are linked to other wider histories surrounding clinical practices of power/knowledge (Parr, 1998b; Philo, 2000; Pile, 1996; Takahashi, 2000).

2.3.2.2 Landscapes of care

Within the geographical literature on mental health discussions around care are important in understanding the relationship between appropriate service provision and the issue of health citizenship. Of particular interest is the tension between adopting hegemonic notions of care that are based in forms of governmentality, i.e. clinical 'care', and the devaluing of forms of care that privilege non expert experiences and knowledges. Different visions of care lead to differing forms of collective organizing and organizational development around mental health issues. Different visions of care also lead to different understandings of the relationship between bodies, knowledges and subjectivities. These issues are problematized by mental health geographers who contrast institutional care provided by the 'clinic', which is identified as dehumanizing, and community care provided by grassroots groups (as well as some private and social service providers) which is identified as more supportive and caring (Dear and Taylor, 1982; Park and Radford, 1997; Philo, 1997). For many geographers this is too simplistic a division, thus, many geographers argue for a more specific and nuanced understanding of the value and expression of care expressed in particular settings (Milligan, 1999; Mohan, 1998; Parr, 1999a; 2000; Park and Radford, 1999). For example, Gleeson and Kearns (2001), using feminist political theory, identify how the geographies, practices and philosophies behind institutional care is more concerned with 'justice', that is, formal abstract rights distributed to patients in an equitable manner, while many voluntary, grassroots groups are more concerned with care as an intersubjective, situated process (Bowden, 1997; Smith, 1998 in Gleeson and Kearns, 2001). Other geographers highlight that there are significant gaps in thinking about the range of different spaces of care and how these places affect different practices and expressions of care (Bondi, 2003; Chouinard, 1997; 1999). There are also gaps in the

geographic literature on the differences within caring practices within self-help discourses, whose place is increasingly important within discussions of landscapes of care (Davidson, 2002).

In order to analyze the specific meanings and production of care within a particular location or geography of care we must explore the ways in which definitions and practice of care shift within the landscape, as well as within a particular service provider over their history. The shifting meanings of care are developed within the work of geographers on the subject of landscapes of care. Landscapes of care, a phrase used by Gleeson and Kearns (2001) refers to the connections between the geographies of service provision, expert knowledge/power and meanings of care. Gleeson and Kearns use the phrase in the context of the de-institutionalization of asylums highlighting how this process is connected to perceptions of institutions as 'uncaring' (see also Philo, 1997). However, drawing on research within this thesis in chapter six on anxiety service provision, the phrase also refers to how service providers and the spaces they occupy are divided in part based on their relationship to care and caring practices. The quality of care, and who provides care are central issues in the geography of service provision for mental health issues such as anxiety. Different forms and delivery of care in clinical and non clinical settings help construct public and individual perceptions of the spaces in which that care is given and differing beliefs about who is and who is not included or considered within those places. Care helps differentiate beliefs about types of knowledges present in particular places or persons.

2.3.3 Citizenship and mental health

2.3.3.1 The 'subject' of health

As is shown in much of the post-medical geographical work the phrase 'health care' is a problematic, disputed and loaded term. Unpacking the meaning of health care is important in the context of this thesis where different understandings of care, and health care in particular, are used to differentiate between processes of health citizenship and the healthy citizen. The use of the term care within health geography draws upon writings of care within other disciplines, notably feminist political theory. These writings help to further explain how meanings of care are spatialised and translated into particular practices, places and persons. This section draws upon those feminist political writings in

order to expand on the geographical insights about disability, mental health, mental health care, and health citizenship in section 2.3.2. While there is some discussion about care within mental health geography and human geography more broadly, there is little direct discussion about autonomy within mental health geography. However, both care and autonomy are issues central to understanding the position of the ADA within a wider health care context, as well as the differences between the healthy citizen and health citizenship. 'Care' and 'autonomy' are issues central to the way in which anxiety service provision is approached and delivered. These issues help inform material throughout the thesis, thus it is important to discuss these concepts, and their relationship to one another in more detail than is done in individual substantive chapters.

2.3.3.2 Unpacking health 'care'

The discursive meanings of the term 'health care' are different for people differently positioned within a health care system. 'Health care' is conventionally defined as the preservation of mental and physical health by preventing or treating illness through services offered by the health profession (APA, 2000; NIMH, 2003). In this way 'health care' is a 'professional' system or structure based upon delivery of services by clinical providers or specialist providers that address the treatment of disease and illness and located in specific clinical settings or by the presence of a health professional. Care involves a relationship between subject/self in which normative clinical knowledges and disciplinary power are internalized, embodied or resisted by individuals. Within a public health system care is an intersubjective process that relies on the person adhering and following guidelines and imperatives of health directed by medical and clinical experts (Lupton, 1995). 'Care' in this sense is an expression of governmentality necessarily for the development of the clinic. Governmentality is a political technology in which practices and techniques align political objectives with the self-governing capabilities of those individuals (Foucault, 1976; Rose, 1992). Within a process of governmentality expert knowledges are translated into practices and hierarchies that are institutionalized and spatialized in concrete forms of power and knowledge (Foucault, 1967; Philo, 2000). It is this form of 'care' and health care that informs the production of a healthy citizen who is obliged to take up and conform to the imperatives and authority of expert clinical systems (Petersen and Lupton, 1998:610). These meanings of care are further unpacked and discussed within chapter six of the thesis.

However many 'clients' of the health care system view 'health care' in different terms. Expectations of care by those who use the systems often combines a view of health care as a system of clinical power, expertise and treatment located in specific contexts with an understanding of care governed in and by relations between individuals and between individuals and groups (Couser, 1997; Nelson, 1997). The communicative distance between these meanings has contributed to the disparity in the delivery of services, dissatisfaction with the quality of the health services, and a decreased sense of empowerment by both patients and health professionals (Frank, 1995). The gap in these expectations of care has also resulted in very important health and social movements, such as the women's health movement, disability awareness and patient advocacy-movements that have resulted in significant changes in the provision of 'health care' (Nelson, 1997). Understanding care in terms of the relationship between self and other has been well developed and critically analyzed within feminist theory. Section 2.2.3.3 draws on that literature in order to more fully recognize the model of health citizenship employed throughout the thesis and to contrast discussions of care found in chapter six.

2.3.3.3 Health citizenship and care - the politics of care

Feminist political discourses of care are implicitly and explicitly discussed throughout the substantive chapters of the thesis and have informed the research process as a whole. Care has often been positioned outside of the political realm as prepolitical and apolitical; either because it is "below", a matter of the private and familial sphere, or "above", a matter of the spiritual and charitable (Tronto, 1996:140). The denigration of care as a political or moral concept is a central concern for feminist and geographical scholarship as the specific contexts of care are often mistaken as the content of care (Tronto, 1996:148). Feminist work on care, could be divided amongst those who focus on the specific and embodied experiences of women, and those who are more critical of the association of care with the celebration of conventional norms of femininity where care in its wider forms is neglected (Mackay, 2001:136). Care becomes associated with activities such as mothering or nursing, or as place based, as something that happens within the private sphere or within specified privatized locations (Noddings, 1984; Ruddick, 1989). Likewise, in the case of health care, care becomes associated with activities involving clinicians or health professionals, or as place based as something which happens within clinical settings, or through the presence of a clinician or health professional. For some

this is too parochial and limited a definition of care and health care, as it fails to adequately address the many ways in which care is exercised, understood, practiced, shaped by social institutions, culturally variable and historically specific (Mackay, 2001).

Care should not just be understood as a psychological quality, but also an activity, ontology, a process, a practice, a political goal and resource. Care involves a complex process that reflects structures of power, the separation of public and private life, notions of autonomy and trust, and our conceptions of self and other. By including care as part of a political vocabulary, spaces, and subjects (such as those who are agoraphobic) previously marginalized and 'othered' from the public realm of politics are considered; pointing to the importance of those silenced voices and 'forgotten' places, increasing the possibility of a broader base of political participation inclusive of the experiences of those with anxiety conditions and the ADAO.

The celebration of care has historically been a central theme within feminist scholarship and a form of criticism of dominant and normative versions of subjectivity, political and moral thought. One influential point in the discourse on care within feminist geography is Carol Gilligan's work on the ethic of care in her text *In a Different Voice* (1982). An ethic of care is often poised as a challenge to existing justice and equality paradigms characterized by an ethic of justice (Mackay, 2001:126). An ethic of justice, associated according to Gilligan with male moral reasoning, is concerned with abstract universal moral rules and principles that are substantively concerned with justice, duty and rights linked to a highly individualized conception of the self. In contrast, an ethic of care, linked to female moral voices, is a form of moral reasoning that highlights the importance of responsibility in the context of interpersonal relationships, and the importance of a moral voice that derive judgments from the contextual details of situations grasped as unique and specific rather than abstract and rule bound (Gilligan, 1982; 1997; Friedman, 1997). Autonomous choice within this framework, unlike within an ethic of justice, is not based on separation from other people, does not invoke the value of objectivity and does not equate fairness with noninterference. In the context of thinking about the healthy citizen and health citizenship an ethic of care is useful. In contrast to versions of selfhood, such as the healthy citizen, found in normative patriarchal contexts that highlight detachment and atomistic individualism described as an ethic of justice; an ethic of care, implies a celebration of connectedness and intersubjectivity, which is important for models of health citizenship.

Gilligan's discussion of an ethic of care has been both widely celebrated and contested by feminist theorists, particularly because the care versus justice debate often falls back on (and relies) on a dualistic system of hetero-patriarchal, racial oppression and stereotype. Claudia Card's work on care in *Gender and Moral Luck* (1996) goes beyond the care versus justice debate arguing for different terms and ways of framing relations of care. Card's work is useful for thinking about issues developed within the substantive chapters to come, notably in chapters six around the distinctions between expert and non-expert and in chapter seven in thinking about relational autonomy. For Card, Gilligan's 'justice and care' hypothesis is about how the responsibilities of different kinds of relationships yield different ethical preoccupations, methods, priorities and even concepts where the considerations of care have been traditionally a priori subordinated to those of justice (Baier 1986; Held, 1997 cited as examples in Card, 1997:648). Care as a gendered issue is still central for Card because a larger share of the responsibilities of certain personal and informal relationships are given to women, while a larger share of the responsibilities of formal and impersonal relationships defined by social institutions to men (Card, 1997:648). Card suggests that Gilligan's description of an ethic of care should be more appropriately termed an ethic of responsibility, understanding responsibility as a capacity for responsiveness in contrast to an ethic of rights based in formal abstract relationships that do not require the same degree of responsiveness (Card, 1996). By an ethic of responsibility what is meant is the ethics of informal and personal relationships, and by an ethics of rights what is meant is the ethics of formal or impersonal relationships.

"I examine the sense of responsibility attaching to informal, often personal relationships, contrasting it with that of formal and impersonal ones, and attaching to it independently of a contrast between justice and care. I argue that formal and impersonal relationships as paradigms of obligation and responsibility have produced arbitrarily biased and probably superficial theory. It is not that justice is superficial. The idea is rather that the ethical significance of basic informal and personal relationships is at least as much of the first order as that of basic social institutions. I argue throughout that a focus on formality is not the only bias in modern ethical theory, but that fairness has also been systematically ignored in personal and informal relationships especially where women are involved" (Card, 1997:649).

Similar to Card, Bowden describes how "the formal associations of citizenship are frequently used to distinguish those aspects of relations between persons in which intimacy is constitutively limited or in which the partiality of personally engaged attentiveness signals unique bias and favoritism" (Bowden, 1997:141). Within the context

of normative citizenship, relations between citizens conventionally rely on norms of conduct that emphasize the impersonal and the impartial. Values of attachment, responsivity and flexibility, typical of caring and impersonal relationships are frequently suppressed by requirements for order, decidedness and consistency within a concept of normative citizenship as well as within normative notions of care associated with a clinical system of anxiety service provision. In this way citizenship, linked to practices of health care, allegedly signals the replacement of care with justice and commitment with duty (Bowden, 1997:142). For Bowden however a model of citizenship is not limited to this. In "recognizing personal practices of caring in the social organization of the public sphere and in the material content of citizenship, public ideals and the notion of the 'public' can be transformed by caring values" (Bowden, 1997:147). For example, volunteer 'care work' carried out by women raising funds for political candidates, conventionally seen as adjunct to official relations- can also function independently in order to foster community solidarity (Adelson in 1994 in Bowden, 1997:150). Bowden argues not only for the importance of a model of health citizenship, but for the importance of programs within the ADAO which may not have as public a face such as the volunteer companion program in fostering a sense of identity, community and subjectivity.

Card's and Bowden's discussion of care reflects a tension in the meaning of health care, as described earlier, between the formal obligations of health care institutions, providers and professionals to provide services and maintain access, and the need for informal interpersonal relationships even within those formal structures. Care and justice as informal and formal is fundamentally connected to systems of power and authority that shape its meaning. In this way Bowden argues that current conceptions of citizenship, produced by a public/private division and a care/justice divide cannot be removed by a simple revaluation of the perspectives and values acquired in personal practices of care (Bowden, 1997:152-3). "State apparatuses of general surveillance", as described by Habermas and Foucault (see chapter six in the thesis), are where professional expertise and bureaucratic process frequently operate to the detriment of personal needs and caring attachments in state clinical and social services, highlight the deep antagonisms between the caring possibilities of personal life and the capacities of the state (Bowden, 1997:161).

In other words what Card and Bowden discuss may help further our understanding behind the tension between the ADAO's adoption of dominant clinical discourses and forms of knowledge and the privileging of its own discourses and the more personal knowledges of

its membership. In a system in which formal associations and institutions overshadow the significance of informal and personal associations, it makes sense that the ADAO believes it would gain more recognition from other services providers and the public at large by being seen to be a part of that formal system of institutional service provision. As Bowden reiterates it is difficult for individuals and groups to express forms of care in a system of state apparatuses of general surveillance. However both Card and Bowden also argue that informal associations and personal relationships are just as important as formal ones, thus it is necessary for the ADAO to recognize what its formal and informal associations have to offer the organization.

A good example of the informal relationships Card and Bowden highlights are relations of friendship. Friendship helps us to rethink meanings of care and justice, and the interplay between these concepts. Friendship according to both Marilyn Friedman (1987) and Peta Bowden (1997) highlights some of the problems inherent within feminist work and the valorization of care. Friedman focuses on friendship as a form of caring practice that does not immediately draw on gendered stereotypes in which both an ethic of care and justice are present (Friedman, 1987; Friedman, 1997:652). Friendship is an issue that is discussed within the context of the research methodology in chapter three, and in the context of the volunteer companion program in chapter eight. For Friedman care and justice, responsibility and rights, are conceptually compatible and complement one another (Friedman, 1997:650). Justice is necessary to moral thinking about interpersonal relationships and care is necessary to moral thinking about social policy (Meyers, 1997:664). Like Friedman, Bowden focuses on how friendship is viewed as a particular form of care, in which care is connected to actively chosen sharing and reciprocity (Bowden, 1997:61). In this way friendship as a form of care is central to the realization of personal potential, identity and the maintenance of community values (Bowden, 1997:62). This is reinforced by Friedman who suggests further that the context of trust and shared perspectives that friendship provides allows us to participate vicariously and explore new standpoints from which we can explore the significance of moral values and standards in the public and private sphere (Friedman, 1987).

Feminist theory has exposed how divisions between concepts and qualities of care and justice are largely arbitrary, yet feminists are also concerned to expose the ways in which dominant political, economic and social discourses obscure the central importance of care, and in so doing relegate the experiences and work of women and the private sphere

to a lesser importance than activities within the public sphere. Joan Tronto's work in *Moral Boundaries: A political argument for an ethic of care* (1993) on care helps further politicize the importance of care and informal/personal relationships in an attempt to politicize much of the work that women do in the private sphere. Further then that, Tronto's core argument is that we must stop associating nurturance, compassion and caring as women's morality, and introduce care as a central political ideal and political practice because it describes what is necessary for citizens to live together in a pluralist society (Mackay, 2001:142). Thus rather than valorize women's morality in an ethic of care, Tronto is concerned to advance the notion of a care ethic.

According to Tronto a care ethic as a political concept involves responsiveness because:

“Responsiveness suggests a different way to understand the needs of others rather than to put ourselves in their position. In instead it suggests that we consider the other's position as the other expresses it. Thus one is engaged from the standpoint of the other, but not simply by presuming that the other is exactly like the self. This requires attentiveness” (Tronto, 1993: 136).

In other words a care ethic is grounded within a politics of difference and the importance of interdependence central to the fostering of relational autonomy discussed in section 2.3.3 and in chapter seven of the thesis. Acceptance of difference, that is difference between individuals and perhaps within one's own sense of self, becomes a positive fact rather than a threat to social stability that would promote self-respect as well as respect for others as crucial social values (Mackay, 2001:153). Interdependence is highlighted within practices of care in a way that implies that we are never fully autonomous, self supporting and disconnected from others. Yet, according to Tronto many political theorists have condemned care as a form of dependence and rather than seeing dependence as a natural part of the human experience, dependence is both character and autonomy destroying (Tronto, 1993:163). In this way dependence is feared and care giving is both devalued and denigrated (MacKay, 2001:145). The result is that those who receive care are often transformed into the 'other' and identified by whatever marks them as needing care; their economic plight, there seeming physical disability and so forth (Tronto, 1993:145). 'Otherness' arises out of our expectation to be autonomous and independent. Thus many people 'other' care givers or care receivers in order to consolidate their own sense of autonomy (Tronto, 1993:124). Care conjures an association with the private, the emotional and the needy; thus care can become a sign of weakness, which results in the devaluation of care as work and the location of care within

trivial, emotional and private states (Tronto, 1993:112). By dismantling the myth of independence, the myth of universalism, that underpins notions of the healthy citizen, is also unmasked. When people are viewed as interdependent their needs become a matter of social, cultural and political concern. (Mackay, 2001:147).

Ultimately the care ethic that Tronto describes must be situated within the context of deep antagonisms that exist within a health care system and the public sphere more broadly. Sevnhuijsen goes one step further than Tronto and Bowden in exploring the relationship between a care ethic and the complexity of the interplay between gender, power, care and ethics, while simultaneously stressing the importance of gender in a care ethic, because we cannot divorce gender or real women's experiences from the development of care thinking (Mackay, 2001:153). For Sevnhuijsen a care ethic needs to be situated within concrete socio political settings and situations (Sevnhuijsen, 1998). Like Tronto, Sevnhuijsen argues that the equation of autonomy and justice within independence within traditional liberal frameworks has led to the privileging of values of self sufficiency and a denigration of care, dependency or interdependency (MacKay, 2001:150). She also identifies how a care ethic and its characteristic practices of attentiveness, responsibility, competence and responsiveness provide the framework for reaching judgments which are attentive to difference and contribute to a radical pluralism (Sevnhuijsen, 1998:14-5 in Mackay, 2001:151). Care rather than a form of identity politics is a form of action and social agency that assists citizens in making political judgments about social provision (MacKay, 2001:150). In effect Sevnhuijsen argues for the importance of health citizenship in which the creation:

“[Of] a space in which carers as citizens can ‘bring their expertise and moral considerations into public debates without being associated with a fixed caring identity or with associated claims to moral truth or moral goodness’ (Sevnhuijsen, 1998:15). Thus the ethics of care gives rise to a form of deliberative citizenship in which embodied citizens seek to judge with care and use attentive reasoning rather than universalist reasoning as their starting point. [Sevnhuijsen] argues that this results in a two fold outcome: first that the ideas of citizenship are better able to accommodate diversity and pluralism; and, second that care is ‘deromanticized’ which better enables us to ‘consider its values as political virtues’” (Sevnhuijsen, 1998: 15 in MacKay, 2001: 151).

Thinking about the usefulness of care as a social and political resource brings to light various issues and concerns developed throughout the thesis culminating in chapter eight around health citizenship and community. The specific contexts of care within anxiety

health practices, as discussed in the context of chapter eight, may suggest that practically care can be an inequitable process, as it involves relations of power, pain and vulnerability that may be abused by either care giver, care receiver or both. Thus the inequalities of caring can be problematic for a politics of care and the development of health citizenship (Tronto, 1996:149). “Because care forces us to think concretely about people’s real needs, and about evaluating how these needs will be met, it introduces questions about what we value into everyday life”(MacKay, 2001:147). A care ethic “frames political issues in such a way that makes their impact and concern with human lives, direct and immediate. Within a care framework, political issues can make sense and connect to each other. Under these conditions political involvement increases dramatically” (Tronto 1993:177 in Mackay, 2001:148).

“[C]are values are skills that are needed in the public sphere of citizenship. The public worth attached to care thinking and care thinkers as citizens’ acts as a powerful form of recognition and validation and can build or reinforce group solidarity. Taken together the ethics of care presents a powerful vision of a different sort of politics” (MacKay, 2001:130).

In this way is care thinking a key tool in improving democratic participation, creating meaningful consultation and forming new forms of deliberative or active citizenship conducive to health citizenship (MacKay, 2001:153)?

2.3.3.4 Health citizenship and autonomy

The issue of autonomy is central to the thesis, and is explored in detail within chapter seven. This review enhances a discussion of autonomy within that chapter by drawing together connections between care and autonomy, and by expanding on and broadening discourses on autonomy within chapter seven. Care is central to feminist political theorizing on autonomy, because if connectedness and interdependence is understood to form the basis by which persons develop and relate to one another, basic suppositions about autonomy must also come into question. Unlike care, feminist discussions around autonomy are not as well developed within mental health geography in spite of its obvious relevance to questions of personhood, self-governance and relations of power. Traditionally autonomy has been the defining ‘lack’ for persons with mental disorders, or those who are labeled deviant, mad or ill. Lack of ability to be autonomous has led to the systemic discrimination of those with mental illness, and the development of beliefs about mental disorder and meanings of the ‘mental’. This is connected to the way in which

autonomy has been defined individualistically in relation to governing the 'mind', as the capacity for rational self-legislation or self-governance that is considered to be the defining features of persons (Rawls, 1971). Framing autonomy as a form of independence from others, and independence of mind has been problematic for many individuals including the mentally ill, and thus it has been important for feminists and mental health advocates to reclaim and re-conceptualize the concept of individual autonomy and to articulate conceptions of choice and political rights that are more adequate from a feminist perspective such as relational autonomy (Hawkins, 1993; Sherwin, 1998).

The term relational autonomy arises from feminist criticism of traditional ideals and notions of autonomy as masculinist, detached, individualistic and rationalistic. Instead autonomy should be seen as a relational and intersubjective process that explodes the myth that personhood can be developed independent of other individuals and life experiences (Koehn, 1999). Many feminist critiques focus attention on the need for a more fine grained and richer account of the autonomous agent as historically embedded while psychically differentiated (Mackenzie and Stoljar, 2000:21). Feminist critiques are also concerned to analyze the specific ways in which oppressive socialization and relationships can impede autonomous agency at the level of: individual formation of desire, beliefs and attitudes; the role that norms and institutions play in shaping the beliefs of agents; as well as, an agent's ability to act on autonomous desires and choices impeded by the agent's own restrictions and social norms (Mackenzie and Stoljar, 2000:19-22).

In relation to discussions of care some feminists argue that traditional ideas of autonomy give normative primacy to independent self-sufficiency and separation from others at the expense of recognition of the value of relations of dependency and interconnection. Since such relations have historically been central to women's lives and symbolically associated with femininity, it is argued that traditional conceptions of autonomy not only devalue women's experience and those values arising from it, such as love, loyalty, friendship, and care, but are also defined in opposition to femininity (Mackenzie and Stoljar, 2000:8-9). Traditional conceptions of autonomy are thus masculinist conceptions. An example of a care critique can be found in Virginia Held's account of the self (Held, 1993; 1997). Her account is based on the work of Nancy Chodorow (1978) and other feminist psychoanalytic thought that focuses on the relationship between mother and child:

“The self... is seen as having both a need for recognition and a need to understand the other, and these needs are seen as compatible. They are created in the context of a mother child interaction and are satisfied in a mutually empathetic relationship... both give and take in a way that not only contributes to the satisfaction of their needs as individuals but also affirms the larger relational unit they compose. Maintaining this larger relational unit then becomes a goal, and maturity is not seen in terms of individual autonomy but in terms of competence in creating and sustaining relationships of empathy and mutual intersubjectivity” (Held, 1993:600).

This analysis of the self and autonomy is based on the work of feminists such as Nancy Chodorow (1978), Jennifer Nedlesky (1991) and Evelyn Fox Keller (1985) who all recommend that autonomy be re-conceptualized so that it is not defined in opposition to femininity or to relations of dependence, care and connection. Evelyn Fox Keller (1985), similar to Meyers, sees autonomy as a kind of competence. She describes two types of autonomy, static and dynamic, that respectively characterize the distinction between traditional masculinist accounts and feminist accounts of autonomy. While dynamic autonomy competence promotes an enhanced sense of self where relatedness to, and dependence on, others is celebrated and welcomed, static autonomy competence is pursued in the interests of mastery and domination and arises from seeing others as a threat to the self, from insecurity about the self, and from fears of dependency and loss of self control (Mackenzie and Stoljar, 2000:10).

Autonomy in the context of mental health and health care is often understood as the person's ability to make authoritative decisions about their own health care. This is a perspective that is central to what Lupton and Petersen (1998) describe as the core of public and private health discourses. Within the health care system autonomy is a universal goal, though it is often a goal that is subverted by the structure of a clinician-patient hierarchy (Hawkins, 1993; Nelson, 1997). Autonomy within health care discourses is often synonymous with the respect for patient rights (Sherwin, 1998; Dyck et al., 2001b). Without a principle of respect for patient autonomy, patients may be subject to abuse or exploitation by clinical professionals. Illness and the health care system tends by its very nature to be paternalistic, thus, it is a system in which subjects become reliant and submissive to professional expertise and care. In this way patients are vulnerable to manipulation and have a reduced ability to exercise and believe in the value of their own types of knowledges (Kleinman, 1988; Frank, 1995). Many patients are easily frightened into overriding their own preferences and following expert advice, or

feel compelled to comply with the demands of clinicians in order to obtain access to other services or medications (Sherwin, 1998).

But even in health care systems that accept the importance of autonomy as a central goal, the effectiveness of practices that actually respect and foster patient autonomy or informed choice and consent is another matter (Sherwin, 1998:24). Some of this problem lies in the meaning of autonomy within health care. Public health, and health care more broadly emphasizes the importance of autonomy in the form of personal responsibility and liability for one's own health care (Lupton and Petersen, 1998). The focus on autonomy in health care generally "focuses on individualistic measures and often neglects that autonomy is a socially situated or relational process, imbued in the political dimensions of multiple relationships that structure an individuals' selfhood" (Sherwin, 1998:19). For Sherwin this view of autonomy is rooted in issues of:

"[P]rivilege and oppression within western cultures, where people raised in an atmosphere of privilege come rather easily to think of themselves as independent and self governing, it feels natural for them to think of themselves as autonomous. Having been taught that they only need to apply themselves to achieve their needs or desires, most think of their successes as self created and deserved, oblivious to the barriers that oppression and disadvantage create, where the failures of others become evidence of those people's unwillingness to exercise autonomy responsibly"(Sherwin, 1998:25).

For Petersen and Lupton the focus on autonomy as individualistic is also problematic as those 'autonomous' decisions made about health care are often relational in the sense that they are directed by expert opinion and clinical professionals, which is often unacknowledged by both clinician and patient. The illusion of choice is one part of the mechanism for controlling behavior in modern western society (Foucault, 1980b).

Autonomy is not only reduced by clinicians themselves, but by the services and treatment options available to people circumscribed by the policies of government and private health care services, where the financial interests of the institution or private service being billed may take priority over the patients preferences or needs (Sherwin, 1998:23). Yet the rhetoric of choice within health care services prevails in spite of obviously circumscribed options that may have little primary interest in the well being of patients.

In this way autonomy within the context of health care needs to be conceived of as a relational process. We need to be able to look at both individual decision-making and

the complex set of relations and policies that promote or constrain an individual's ability to make particular choices (Sherwin, 1998:32). By viewing autonomy as relational the process of making decisions about one's health and health care becomes an act of self-reflection in which self-discovery and self-definition are more plausible.

2.5 Conclusion

The objective of the literature review has been to present material that builds on themes central to the thesis and therefore informs the substantive thesis chapters to come. The literature review specifically focuses on geographical and feminist discourses that pertain to the collective organizing of the ADAO. It is hoped that the thesis will make an original contribution to wider debates in human geography and feminist political theory as well as connect those discourses to one another in innovative and productive ways. The substantive chapters of this thesis elaborate on the themes developed within this chapter in order to present an informed engagement with experiences of anxiety conditions. However, before delving into the substantive chapters of the thesis two other chapters, one dealing with the methodological aspects of this project (chapter three) and the other providing background information about the ADAO (chapter four), will be discussed.

Chapter Three - Methodology

3.1 Introduction

Following chapter two's review of literatures pertinent to the thesis, this chapter turns to methodological issues. This chapter describes the feminist methodological frameworks used within the research process. I discuss various methodological considerations, including how data were collected, how these data were analyzed and the process of writing up. Within the research process a variety of qualitative and quantitative methods were used. Feminist scholars encourage a plurality of methods, where the choice of methods is deemed to be comfortable, appropriate or effective (Tuana, 1993). The framework used for this chapter is based on Beverly Skeggs (1995) discussion of methodology within the production of feminist theory. Skeggs poses several questions for methodological consideration (1995:5). First, why was the area of study chosen? Second, which frameworks of established knowledge were used, referred to, challenged, ignored and why? Third, which methods were chosen for the study and why? Fourth, what frameworks of interpretation and analysis were chosen and why? Fifth, what were the processes of writing-up influence in constructing a final product? I conclude this chapter by reflecting on the methodological process employed in this thesis project and asking what kinds of conclusions one can draw from that process about feminist geographical methodologies.

3.2 Question 1- Motivations behind the research

Feminist research is concerned with exploring those voices who may have been silenced or unheard. This was part of my impetus for working with the anxiety disorders association of Ontario (ADAO). I felt that my research, its theoretical framework and direction, should be informed directly by the experiences of those who have anxiety conditions (notably panic and agoraphobia) and by the experiences of organizations that deal with anxiety conditions. My motivation for this research is threefold: first, linked to a desire to change the way in which anxiety conditions are understood and thought of; second, to challenge dominant bio-medical approaches to anxiety conditions such as panic and agoraphobia; and third, to introduce the ADAO to a wider academic audience. Researching grassroots communities, such as the ADAO, involves a critique and analysis of the power relations involved in clinical and non-clinical practices and knowledges. By

focusing on the ADAO, and its varied experiences in the context of health services within Ottawa, I was provided with a starting point for asking new and critical questions about knowledge practices and power relations that are constitutive of the identities and communities that have shaped the ADAO.

My motivation for both my masters and doctoral research was not based on personal experience or identity politics. I have never had a panic or anxiety attack or an agoraphobic episode. My primary motivation was to address a gap in the social sciences and humanities literature because the experiences of those with anxiety conditions have much to contribute to the study of geography in particular. The assumption that a researcher must share the identity politics of those they work with or study can be problematic. Often identity politics revolves around narrow categorizations of a subject or community. For example, many of my interviewees have, at one time or another, been debilitated by the effects of anxiety, panic and agoraphobia, which have marginalized them in various ways. But to say that the defining characteristic of that person revolves around their panic or agoraphobia may be inaccurate, even for individuals who have had panic, or been agoraphobic for a prolonged period of time.

3.3 Question 2- Methodological frameworks - key themes of feminist geography and methodology

3.3.1 Feminist methodologies

I chose to work with feminist methodologies, and the methodological concerns indicated by feminist geographers, because feminist geography is concerned with tracing and exploring the silences and fissures within the discipline of geography. A concern of feminist geographers is that critical methodologies and theoretical perspectives be deployed to include those typically excluded from studies, especially women (Nast, 1994:55). This was one of the reasons I wanted to work with the anxiety disorders association of Ontario whose work has been ignored or unheard. By exploring those gaps and fissures created by, and within the research, feminist geographers explore the possibilities of those 'in-between spaces' for social and political change and therefore create new knowledges and spaces for feminism (Desbiens, 1999). In particular, feminist geographers explore gender biases within methodology, theory and the profession itself.

They also challenge more orthodox and conventional geographic work. This challenge involves:

“[R]ethinking categories, definitions and concepts used to formulate theories within a geographical discipline. Second, it involves examining the methods (and the theories underlining them) used for exploring defined problems. Third it involves considering the process of selecting problems deemed to be significant for geographical enquiry, in particular through using gender (with all its multiple meanings and intersections with other aspects of social identity) as a key analytical category in studies of space/place, environment and landscape” (Madge et al., 1997:86).

Increasingly feminist geographical methods have involved breaking or recreating boundaries, and creating dynamic, discursive and relational spaces that continually produce new understandings and new surprises (Laurie et al., 1999). The researcher herself is seen as reconstructed through the research process, within a fragmented space of fragile and fluid networks of connections and gaps (Rose, 1997). The research process is not one in which the researcher is firmly located; it is a process in which “absences, fallibility, and moments that require translation are brought into visibility” (Pratt, 2000:642).

Issues of methodology are central to feminist geographical projects and have increased our attentiveness to issues of reflexivity, representation and responsibility within research projects. Though methodology cannot provide the grounds for unifying feminists, as feminists cannot claim a single distinctive set of methods in social research, most feminists and feminist geographers agree that the world and theory are not separate from one another and that our theory and methodology are shaped by our embeddedness within the world. By recognizing that theory is embedded in ‘everyday’ contexts, feminist geographers have brought to the fore the importance of ‘geography’ or space and place through issues of the ‘field’ (Jones III, Nast and Roberts, 1997:xxvii).

3.3.2 The ‘field’

Within feminist geography discourses on the ‘field’ are central to a discussion of methodology, the politics of fieldwork and representation of subjects. Historically the ‘field’ has been treated as a physical place, a place to go ‘out’ and do research. In this sense geographers are seen to engage in fieldwork by entering a physically designated

'field' (Nast, 1994:56). This is a reflection of geography's historical reliance on empirically grounded research and an 'objective' stance where researcher and researched roles and positions are clearly defined (England, 1994). The designation of the 'field' as occupying a specific geographic place and researcher location has been heavily criticized by feminist geographers (The Professional Geographer, 1994; Women and Geography study group, 1997; Laurie et al., 1999). Instead for these geographers the field is not conceptualized and actualized in terms of a place or a people, rather it is located and defined in terms of specific political objectives that cut across both time and space (Nast, 1994: 57). As Heidi Nast notes:

"The field is a social terrain in which we, as researchers, can strengthen " through direct experience, the academic foundation of knowledge (Kobayashi, 1994:79) thereby forging bonds between the academy (itself a 'field') and the world at large" (Nast, 1994:57).

The 'field' involves relationships formed with people and the decision making processes involved in developing research agendas and adopting specific research techniques (Laurie et al., 1999:46). Feminist geographers argue further that the field is a site of betweenness that highlights how we always work with others who are separate and different from ourselves. In other words: "betweenness is the: recognition that we cannot fully understand other's subjectivities and speak with authority for them (Staeheli and Lawson in Laurie et al., 1999:51).

Realizing that our methodologies shape and are shaped by the political context and scale of a 'field' means that particular qualitative methods cannot be idealized in an of themselves and that we should not expect that our own motives or the motives of the researched are transparent (Nast, 1994:60). The field should be problematised as it is constructed through power relations that define both the people and places that we study (Staeheli and Lawson, 1994:97). The 'field' is both a discursive and spatial practice that is constituted through power relations that do not end with the completion of interviews, it is (re)produced and (re)negotiated within the context of interpretation, analysis and writing up of the research.

Doing 'fieldwork' involves thinking about and working through a variety of issues discussed within feminist methodology. They include issues such as: power relations,

authority and empowerment within the research; knowledge production and sharing; positionality and representation; friendship and trust; and reflexivity and responsibility within the research. These issues help to identify how researchers and their subjects are situated with respect to the knowledge that is produced, which involves an exploration of the social experience of both the researcher and the researched (Ahmed et al., 2000; Amit, 2000). All of these themes are integral to one another and the distinction of these ideas into separate discussions is artificial.

3.3.3 Authority, Power, and Empowerment

Geographical knowledge is always partial, socially situated and are produced within a political context (Kobayashi, 1994; Rose, 1997). Thus, both researchers and researched are positioned simultaneously in a number of fields of 'power', including gender, age, class, ethnicity, race, sexuality and so on, that are articulated as "positions" in a multidimensional geography of power relations (Rose, 1997:308). The researcher inevitably participates in the (re)production of power relations in the 'field'. However, the researcher will never be able to fully account for the power relations inherent within research or that all aspects of the research can be known (Rose, 1993). Within feminist research a predominant concern is the balancing of power differentials, and relationships within the 'field'. The assumption here is that because the researcher has the last word, it is the researcher who has the 'power' and negotiates that power. As researchers we should both attempt to work against the subordination of the researched, as well as providing safeguards for our own possible subordination and exploitation within the field (Ansell, 2001:103). The researcher needs to be aware that s/he is situated within a context where s/he may be powerless at times (Barker and Smith, 2001; Horton, 2001). There are practical concerns around the politics of doing research under conditions where one's legitimacy is not only visibly in question but subject to constant revision (Kobayashi, 1994:75). Resistance to the research came in a variety of forms, from denying or simply not responding to a request to be interviewed, refusing to answer various questions and limiting the detail and content of the narrative account. If research subjects do not consent to be interviewed, do not show up for a scheduled interview, or do not acknowledge the researcher's presence there is little the researcher can do to balance power relations with those individuals. This became particularly evident when I approached various clinicians for an interview, who felt that as a geographer I had no

authority or legitimacy in doing research on a clinical subject. Thus, the researched hold a great deal of power through withholding or providing access to their knowledge and information. Yet, there are times when we must try to work with those more powerful than ourselves, and who may have agendas that are oppressive (Nast, 1994:59). Every 'field' is a site of negotiation and struggle for power and that the politics of doing fieldwork will inevitably come up against the politics of the 'field' (Kobayashi, 1994:79).

Much of the resistance to the research is also concerned with the notion of expert knowledges and who possesses expertise. My experience in trying to interview various persons illustrated how the power relation of 'expert' knowledge is not always conferred to the researcher. I was both upset and disappointed by the lack of interest on the part of some people I tried to contact, because I genuinely wanted to include their voices within the research. I asked a number of clinicians and academics who were willing to be interviewed why this could be the case, in the hope that they would provide me with ideas of how to attract interest in the research. I was given a number of reasons as to why I was being 'shut out', from: "they just might be very busy"; to "if they could bill you for your time maybe they would do it then"; to "well, you are just a Ph.D. student in geography to them you're nobody". While these responses provide me with some insight into the reasons for difficulty with some interviews, I can only speculate as to why I did not get responses to my request for interview.

Yet, as a researcher I am never entirely 'powerless' because if I cannot acquire certain kinds of information or get enough people to interview, I can always change the way in which I do my research and approach my subject. As the researcher I have control over what voices are heard and how the subject matter is presented. This is why consideration of whether or not the research is empowering, or places the participants of the research in a detrimental position is important. While I have not explicitly set out to empower the researched, increasing the number of people and kinds of audiences for the ADAO is a form of empowerment/consciousness raising exercise that I have explicitly aimed for in the research. Some feminist theorists insist that a feminist project is concerned with the redistribution of power amongst women and men through empowerment of its subjects (See Reinharz, 1992; Wolf, 1996). Unfortunately many researchers fail to ask the research subjects themselves if they are benefiting from the process (Patai, 1991 in Wolf 1996). Who the research is empowering is a pivotal research consideration and question.

Are we concerned with the empowerment of our research subjects, or do “our good intentions mask that the only individuals we are empowering are ourselves” (Moss, 1995)? Is the research about “giving voice” to others as a means of empowerment, or is it about allowing others to speak and be heard in their own voices?

3.3.4 Whose knowledges? knowledge production and knowledge sharing

The issue of sharing knowledge within the ‘field’, or giving back to the participants, is an important issue within feminist geography. A central issue for feminism has been the development of methods for working with women that are fully consultative and open (Smith, 1993). Feminism implies an obligation to take moral responsibility for our politics, a general ethic of accountability towards the subjects of research and responsibility for the way that knowledge is produced (Holland et al, 1998:16). The researched should not be treated as mines of information to be exploited by the researcher as a neutral collection of ‘facts’ (England, 1994:82). But how that sharing process is initiated and what is given back needs to be considered, because not all products of the research may be useful for those researched (Morris-Roberts, 2001:148). For example feeding back research findings to the participants, without consideration as to the form of the feedback, may mean little to the researched (Mathews et al., 1998:103). Within my own research I chose to share information and often act as a go between or messenger for various participants and different people within the city.

For example, I was asked by the executive director to contact another person to find out if he would be interested in potentially helping the ADAO in some way and I did so. In another example, while interviewing information was relayed to me by a clinician that would have been very useful for the ADAO to have known. Because ADAO members provided me with a wealth of knowledge for my research, to what extent was I obliged to reciprocate that generosity? Did the ADAO want me to share my knowledges that I had gained within the ‘field’ with them? I wanted to share what I had learnt with the ADAO, but I did not want to impose my desire on the researched. I phoned the executive director, and mentioned to her that I felt that the research relationship was very one sided and that I wanted to share some of the knowledge I had gathered with the ADAO. She was happy to hear this and informed me that there was a recent discussion of my research during a board meeting. In this instance the researched were happy to be engaged in the process of



knowledge sharing. However, knowledge production and the sharing of knowledges were not always possible within my research. Some interviewees wanted me to inform them of gossip collected through the research, which I felt was inappropriate. Alternately, not all interviewees were interested in the research outside of the context of their own interviews. I presented some of my analyses to my interview subjects throughout the course of the research in order to get their opinions about my interpretations. The process yielded a lot of critical feedback, but many interviewees were not concerned with what was done with the research material. In this way feedback is often an imposition upon the research participants who may have little time or interest in the research itself.

There are times when the distance that a researcher may have from the research subjects may help to inform the researched of things that may be too close for them to see. My position as researcher allowed me to hear and explore knowledges and perspectives that the members of the ADAO may have not had access to, or been afraid to contact, thus, the sharing and reciprocity of knowledges across researcher, researched boundaries was central to the research. In so doing I was involved in a process of representation of both others, and myself that is a part of the larger process by which identities are inscribed (Dyck, 1998; 1999). Within the research it is important to view the researched as collaborators and to share knowledges back and forth with them. In this way I was attempting to give back to my participants through forwarding information, listening to and facilitating their experiences within the research.

3.3.5 Positionality, trust and friendship

Feminist methods position the participant as someone who informs the researcher about the processes and relations under study, in contrast to a situation where the researcher is viewed as an expert on a separate plane from the subjects of the study (Herman and Mattingly, 2001; Oberhauser, 1997:167). Methodologies that promote mutual respect between researcher and researched in non authoritative ways are deemed preferable in that they allow for others to be heard and potentially empowered (Nast, 1994:58) As feminist scholars we should recognize the intersubjectiveness of the relations between a researcher and her/his subjects, and that as a consequence the knowledge that is acquired is subjective and interpersonal (Dyck, 1997:186). By situating 'fieldwork' in the multiple contexts in which we operate, feminist geographers have highlighted how the role of

researcher is constituted in a space of 'betweenness' in which roles are constantly changing (Robson, 2001). Not only did I behave differently in different situations (sometimes quite unconsciously- though I could later hear and read this difference in my interview transcripts), but also the people I interviewed interpreted me in different ways.

The differential positioning of research and researched is intimately tied to the respective relationship of each to a particular place and personal location as experienced through specific socio-spatial settings (Dyck, 1997). I often moved back and forth in my own researcher positioning from supplicant to an informant/knower. Many feminists favor the role of supplicant, where the researcher explicitly acknowledges her reliance on the research subject to provide insight because the knowledge of the person being researched is greater than that of the researcher (Oberhauser, 1997). The appeal of supplication is in its potential for dealing with asymmetrical and potentially exploitative power relations by shifting a lot of power over to the researched, even though this may mean that the researcher becomes very dependent on the researched for knowledge (England, 1994:82). Both researcher and researched come to the research with their own purposes and expectations, some of which were expressed to me and some that remained hidden (Herman and Mattingly, 2001; Ley and Mountz, 2001). I was not always forthright about how much information I knew, in order that the interviewee could tell me in his or her own words about a situation or person.

Another issue central to positionality for researchers studying anxiety conditions is not to assume the role of therapist (Burman, 1998; Ussher, 1989). Invariably, certain research subjects are looking for someone to assist them, to tell them what to do and to talk to (Sandeloski, 2002). Many are hoping the researcher will act in a judgmental and prescriptive role as therapist. However, I am not comfortable being positioned as someone who can solve their problems because while I have studied anxiety 'disorders' extensively, I do not have the skills to counsel those I interview. Therefore, it was important to clearly inform the researched, that the interview sessions may be illuminating for them and they may learn things during the course of the interview about themselves, but I cannot address or solve their immediate problems. Indeed, I stressed to interviewees that I am not necessarily the expert in the relationship and that the research findings are contingent on the expert knowledges of the researched.

Often discussions of positionality revolve around the issue of who is inside and outside of the field and the development of friendship in the research context (Ribbens and Edwards, 1998). My position as an insider /outsider consistently shifted within the communities that I engaged with over time. I was an insider in the sense that I had a long-term contact with the ADAO and have followed its progress since 1997, which placed me in a privileged position from which to speak from and to the ADAO. The role of friendship was a part of how I negotiated that insider/outsider position. Earlier feminist works suggest that developing friendships between the researched and the researcher is desirable and necessary for productive feminist research (Oakley, 1981; Finch, 1984). These works were a critique of interviewing methods that favored detachment and rigid divisions between the identities of researched and researcher. More recent feminist scholarship suggests that friendship within the research process is not always possible, and does not always result in a balanced power relation between individuals (Cotterill, 1992). The development of friendship within the 'field' is further complicated because:

“[T]he friendship that may develop between a feminist researcher and her subject could end up being more manipulative than traditional positivist methods... Friends end up knowing more about each other than conventional researchers and their subjects; this closeness can expose research subjects to far greater danger and exploitation” (Stacey, 1991:114 in Wolf, 1996: 20).

If a researcher seeks friendship, friendship needs to be specifically defined as a mutually respectful and reciprocal relationship during the research process. Striving for empathy and intimacy should not be confused with friendship (Reinharz, 1992).

3.3.6 Reflexivity

Reflexivity, or the relationship of a researcher to their research, is also a key issue within feminist geography. Reflexivity needs to be used throughout the processes of locating, reaching out to, and working within a particular 'field' (Nast, 1994:59). Reflexivity is often misunderstood as narcissistic and navel gazing, that the researcher has let the “veil of neutrality slip” (Oakley, 1992). Rather, reflexivity is “self-critical sympathetic introspection and the self-conscious analytical scrutiny of the self as researcher” (England, 1994:82). For example, I often used a journal in order to reflect on perceptions and interpretations of the research (also see Hovorka, 1997). It is necessary for a researcher to have a personal space in which to reflect and perhaps to conceal aspects and gaps within

the fieldwork that they are not happy with or proud of. This can be beneficial and problematic for both researcher and researched. However personal journals are also a way in which the researcher can critically reflect on the process of research in ways that are translated into further obvious fieldwork (Hertz, 1997). Reflexivity is critical to the conduct of fieldwork it induces self-discovery that can lead to new insights about research questions, and result in more openness to challenging one's theoretical position (England, 1994:82).

Reflexivity provides an opportunity for the researcher to consider whether the research has obscured and displaced the research subject in favor of the researcher, giving voice to the already speaking author (Lal, 1996). This is a concern because it may perhaps further silence subjects that have typically remained unheard. On the other hand, it may also mean that the practices of the research subjects, who may be in a politically disadvantageous situation, are not exposed as easily to those who may use this knowledge to oppress them (Madge et al., 1997:108). For example, I am concerned that the research may expose certain individuals to unfair scrutiny. I am also conscious that I need to consider what effect my analysis will have on the changing dynamics of anxiety service provision in Ottawa and beyond. The act of choosing and working with marginalized groups involves a critical and reflexive questioning of what the researcher and research hopes to accomplish, why a particular area was chosen, and for whom we are working (Nast, 1994:58). This also involves reflecting on how power is negotiated between researched and researcher and how these positions have transformed themselves in order to maintain honesty between the researcher and the researched (Du Bois, 1983:95). There needs to be a recognition that some historical and material realities are beyond our personal and social reach, for example my ability to affect change and convince institutional clinicians of various issues. Just because we want our research to effect social change does not mean that we will be able to. Such expectations ignore our personal limits within our specific socio-cultural locations (Nast, 1994:59).

3.4 Question Three- Methods

3.4.1 Selecting a case study- the organization

According to Del Casino et al. (2000:523) researcher recognition that the selection of objects/subjects of analysis, such as an organization, is a key moment in the

methodological process. Those objects/subjects of analysis affect the appropriateness of the research questions we ask. Organizations are valid and theoretically complex objects of analysis for geographers. Geographies are produced through organizational activity as individuals who network within and outside of organizations “stamp their ideological and material impression regions and landscapes, they help individual-level spatial behaviors, they influence geographic perceptions, values and meanings, they direct and redirect the unfolding socio-spatial relations”, in other words organizations both internalize, negotiate and create social space (Del Casino et al., 2000:524). In this way studying organizations provides a means of understanding wider social and spatial processes, patterns and discourses. The study of organizations, whether as a single case study or as comparatively studied alongside other organizations, helps the researcher frame their inquiries in order to begin to understand the complexity of socio-spatial settings (see Conradson, 2003).

Given my working knowledge of and relationship with members of the ADAO I based my research primarily on a single case study. Using a single case study was, as I discuss later in the chapter, not initially of my own choosing. Yet, practically using a single case study allowed me to direct and focus the research material and analysis more precisely on discourses and issues of special concern expressed within the organization. By focusing on the ADAO, and providing some comparative analysis and context, a set of questions and discourses emerged internal to the organization helped refine interview questions for interviewees both internal and external to the organization. Additionally, because of my prior association with the organization interviews were easier to facilitate and interviewees were more open and candid in their discussions. The choice to focus on the ADAO made many interviewee's feel 'safer' within the context of interviews because they felt that I was genuinely interested in the organization and its well-being (see Conradson's discussion of empathetic warmth, 2003:512). However using a single case study also has significant implications and drawbacks for the theoretical claims that can be made within the thesis. First, a single case study has methodological implications for issues of trust and researcher positionality as discussed in section two of this chapter. Second, the ability to understand the wider context of mental health issues is framed by the experience and perspectives of interviewees within the group that may be limited and partial or at times speculative and uniformed. In this way the thesis may not provide as nuanced or complete an understanding of the wider context of health service provision. For example, as the ADAO is dominated by a particular individual and group of

individuals selected by those individuals viewpoints expressed are partial and biased, and that other power and discourse dynamics will occur within the research process (Hovorka, 1997). However, as many researchers point out, all research is limited and partial in some way, and the search for a 'complete picture' is problematic. It is thus important for any researcher to acknowledge the limits of their research questions, analysis and work (Bondi et al., 2002). This does not mean that researchers who work with single case studies or comparative studies cannot be thorough and methodical in their analysis and writing up or that their work is somehow less valid. Recognizing, however, that further work and research that the work is a stepping-stone to other analysis is important.

Often feminists who research specific organizations and single case studies employ an ethnographic approach to their research. Ethnography refers to research that involves participating and observing in particular socio-spatial settings in order to understand people's lives from the 'inside' within the context of their everyday lives and experiences (Parr, 2001:182). Here the researcher is often closely involved with a particular group or neighborhood where attention is paid to the social structures, behaviors and meanings of these for that group (Hay, 2000: 187). Ethnographic approaches explicitly discuss how researchers may affect the research context as they become a part of the social world that they study, as well as the importance of reflexivity on the social processes, personal characteristics and values of the researcher which inform the collection of data and its analysis (Punch, 2001:166).

While the research I conducted bears many similarities to the concerns raised through ethnographic research an ethnographic study of the ADAO would have been difficult and not necessarily useful. There are two primary reasons why ethnography was not deemed appropriate for the study. First, most of the places in which ADAO activity occurs are within the private residences of members, or spaces that are far too small to accommodate more than one person. The ADAO headquarters were for many years located in the executive director's apartment, performing ethnographic study within a small two bedroom apartment turned office would be uncomfortable (for both myself and those in the office), intrusive, and a violation (perhaps) at times of the executive director's privacy. The office located in the Bronson center is roughly four feet wide by eight feet deep, complaints were made by office staff about their own ability to work within the space, having an additional person in the office would be very uncomfortable physically and

mentally. Secondly, the ADAO did not operate in consistent patterns, the days of the week that staff worked in the office varied significantly and were often not well planned. In this way it would be practically difficult to arrange for constant periods of observation. Third, while I attended various meetings and events held by the ADAO, it was difficult within support groups and the fourteen week anxiety management program to have every member agree for me to sit in or observe the group. At times I would attend a group session and be asked to leave because someone in the group was having a bad day, or because they felt vulnerable by my presence as a researcher. As Parr notes research strategies such as ethnography may serve to reinforce the vulnerability of the people who live in those spaces, as the presence of the researcher may also serve to help objectify the researched (Parr, 2001:192). In this way researchers seeking to help empower those they research by focusing and intruding on their lived experiences can reproduce the processes they seek to critique (Parr, 2001:191).

Yet similar to many ethnographic studies, I was cognizant of my positionality within the context of research settings and made records of my observations throughout the research with a focus on how people reacted to my questions or myself. I was reflexive on the nature of the relationship between myself and research participants, as well as how that relationship transformed over time. Often ethnographic researchers are initially positioned outside of the communities they study, while my position and my relationship to the ADAO placed me in a position where I was not quite an insider or outsider. This both facilitated certain relationships and flow of information at the same time as it hindered other relationships and information exchange, which was important to record, discuss and analyze within the context of the research (Punch, 1996: 2001). Ultimately, it is important for the researcher (performing ethnography or not) to understand that negotiating access in different contexts hold different implications for the formation of research relationships and creating geographical knowledges (Parr, 2001:192).

3.4.1 The interview process - collecting 'data'.

I have worked with the ADAO since 1997. In this period I often collaborated with the current executive director Cheryl Driskell. Throughout this period I demonstrated my commitment to the organization and its mandate through my work on panic and agoraphobia and my genuine desire to explore issues that are influenced by, and pertain

to, individuals with anxiety conditions. As a result it was not difficult for me to collect information and gather people for interviews who are associated with the ADAO. When I came back to Ottawa to initiate the research interview process in October 2000 I contacted Cheryl, informed her of my research on community based organizations that deal with agoraphobia and panic, and my desire to more specifically look at the ADAO's structure and programs. I then asked her if I could interview her, and if I could have a list of other names of people to interview. She was happy to be interviewed and provided me with the names of other ADAO members. Thus Cheryl was a key person in providing me with my initial network of interviews, which came to influence the research directly, in terms of whose experiences I had direct access to. It also was very revealing in that it exposed issues of power within the larger health services community.

In total twenty-seven formal interviews, thirty informal conversations and twelve follow up interviews were conducted during the period of October 2000 to December 2001. The interviewees ranged in age from 18-65, were predominantly white females of differing ethnicities, of middle to upper class backgrounds with a university education. The interviews were semi-structured, typically lasted from one to two hours in length and were tape-recorded. Interviewees were offered access to see the transcripts if they wanted. I had a long list of questions under various headings that would be asked depending on the role of the person (staff, board, volunteer, consultant) and their knowledges or experiences with anxiety/panic/agoraphobia and the ADAO (see Appendix III and IV- for interview schedules). The interview questions always began with a series of introductory questions about the person themselves. While I thought that this was a good way to ease into some of the other questions about the ADAO or individual experiences of panic and anxiety, I found that many of the people were confused by my interest in their lives outside of their involvement with the ADAO. After interviews many people responded by saying that they did not expect a lot of the questions, and did not realize that I was 'interested in their lives and opinions', they 'just thought I wanted information from them'. I also always concluded the interview by asking the person if they knew other people that would be interesting to interview, if they had any questions for me, and if they had any suggestions of research questions or themes that they would want to see be developed or researched. Some interviewees were interviewed again in follow up interviews, or asked to be interviewed again after they received copies of their transcripts. After each interview, informal conversation, and at different points during the research, notes were made in a

separate journal to reflect on the research process. This journal would influence the creation of thematic codes, but journal material, which was often from confidential informal conversations are not directly quoted, unless the interviewee gave permission to do so.

Language played an important role in the construction of my interview schedule. Certain words that are commonplace in discussions within political philosophy or feminist geography were not appropriate for use in the context of an interview for a variety of reasons. For example, I found it difficult and unhelpful to ask my interviewees questions about citizenship using the term citizenship because most of those interviewed understood that term within discourses on the nation state. In this way, using the term citizenship did not contribute anything new to an understanding of what role citizenship plays in their lives. They would talk about voting, being able to attend Canada day celebrations and so forth. Yet, discussions around alternative medicine contributed to interesting discussions on being un-Canadian that would bridge further discussions about forms of health citizenship. Some interviewees, particularly those who were service providers in social work or health care institutions, were aware and frequently used theoretical language. For example, one interviewee suggested that I should more appropriately use the term interdependence, as opposed to independence or dependence.

I began my interviews by interviewing Cheryl at her home. I presented her with a letter of introduction that further outlined the purpose of my research and an informed consent form that gave her the opportunity to choose whether or not she wanted her interview to remain confidential (see Appendix I for letter of introduction and Appendix II for informed consent form). I informed all of the research interviewees that their decision about confidentiality could be changed. If they did not want a part of the interview to be identified with them or if they wanted to be taken off the transcript they should mention it during the interview or phone me afterwards. Additionally interviewees were told that they could stop the interview at any time that they were uncomfortable. Every interviewee was presented with my business card, a letter of introduction and informed consent form (all on University of Edinburgh letterhead to verify and legitimate my position as a researcher). After the interview Cheryl presented me with a list of names and contact numbers for current staff and board members of the ADAO, she also told me that she had contacted all of those on the list and informed them that I would be phoning for an

interview. Cheryl's seal of approval from the executive director was instrumental with the ease with which I received consent from those on the list to be interviewed. When I contacted the names on the list I mentioned that Cheryl had suggested that they would be interesting and useful to speak with, which made those that I contacted more comfortable with the request for an interview.

During the interviews I actively listened to interviewees' stories, asking questions to some and not others in order to ascertain which paths to take and which issues to follow up, which to ignore, and which to probe further. While I was guided by an initial set of questions which on an interview schedule that were developed for different interviewees, for example, board members would be asked different questions than long term volunteers (see Appendix III). At each interview I was guided by what the participant said to me and my interpretation and understanding of their words, this led to the shaping of different interview questions (see Appendix IV). The interview content was therefore a joint production. After each interview questions would be refined, as would my approach to asking questions and listening to respondents. This dialogical processes between my interviewees and me continuously helped to shape the structure and questions of the interview as well as the interpretations of the narratives that were produced later on (Ribbens and Edwards, 1998; Smith, 2001). This dialogue increases the probability that the research may be transformed by the input of the researched and second and highlights how the researcher is a visible and integral part of the research setting (England, 1994:84).

What was more time consuming and difficult was organizing the specific time and place of the interview. The interviews occurred in a wide variety of places chosen by those interviewed such as; people's homes, coffee shops, shopping centers, work offices and most commonly at the ADAO's new office in the Bronson Centre. The centre may have been a practical venue to meet in, but a horrible space for recording interviews due to echo. I encouraged the interviewees to choose spaces in which they felt comfortable or spaces that were convenient for them. I did so in order to address issues of unequal hierarchies or levels of control that are perpetuated and (re) created within fieldwork (Wolf, 1996). Unfortunately, as comfortable as those spaces were, some of the locations turned out to be horrible for transcribing later on, and in future interviewing I might be more forthright in setting up interview locations.

After I contacted all of the current staff and board members for interviews I went back to Cheryl to ask her for additional names of people, such as long term volunteers and consultants, who might be interested in being interviewed. I was provided with additional names that I contacted, and almost all replied and consented to be interviewed. At the same time as I was interviewing persons from the list of names provided for me by Cheryl, I was also attempting to contact clinicians within private practice clinics in the Ottawa area and clinicians in key mental health institutions such as the Royal Ottawa Hospital (ROH), which had recently opened up a new anxiety disorders unit. I had no luck in contacting any clinician from a private clinic and only interviewed three clinicians at the Royal Ottawa for the entire year that I was in Ottawa. However, I was able to contact and interview a variety of staff from the anxiety unit at the Royal Ottawa from names given to me by Cheryl. Because of my inability to contact these individuals, I consulted and interviewed a number of individuals in key health service positions, counseling centers, and academic institutions within the city to find out if there were other networks I could tap into. Based on their suggestions I made more contacts with health services such as the Canadian mental health association (CMHA) an organization that is central to the implementation of services within the city as a contact between community groups, institutions and the public.

In addition to semi-structured interviews I also collected data about the ADAO through documents provided to me by the organization. These data included: copies of newsletters; statistics on phone calls and questions received by the office; evaluation forms from programs that the ADAO offers; copies of booklets; handouts; training workbooks; statistics on numbers of participants and volunteers; protocols; scripts for projects; workbooks designed for the youth education program; board meeting minutes; copies of proposals for funding and rejection letters. Essentially I was given access to most of the documents in the ADAO office. The collection of this data has been valuable in comparative analysis of the semi-structured interviews. I found that a comparison of the accounts of those I interviewed and the quantitative documents suggested different and often contradictory information about the ADAO. For example, interviewees discussed how the ADAO had grown exponentially over the past five years, however statistics suggested otherwise. This forced me to rethink and reanalyze material gathered during the interview context. The data from the documents are useful as: a record of changing discourses, programs and structures within the ADAO; as an evaluative and comparative

tool between the written guidelines of the ADAO and the experiences as described to me by those interviewed; and as information that contributes to a wider literature on anxiety conditions.

3.5 Question 4- Frameworks of analysis and interpretation

3.5.1 Transcribing

The process of transcription can be difficult, time consuming and tiring. But, transcribing for hours means you become intimately acquainted with the discussions and memories of those interviewed. It also means that often the excitement of the initial experience is turned into boredom. The process of transcribing highlights gaps that may occur between the written and spoken word, as well as, gaps between the spoken word and the academic presentation of those words. The interviews were transcribed using a transcribing machine and took from between two to four hours per hour of interview to transcribe depending on the quality of the tape. In transcribing my intention was to get as much of the conversation as possible on paper. Voice intonation, punctuation pauses and other sounds would be included during a second transcribing session. The first transcripts had the appearance of run-on text. The division between speakers was indicated not through name but through separation of paragraph. Participants who asked for copies of the transcript had name headings included and correct punctuation.

While my initial intention was to transcribe all the interviews myself, this became impractical at one point during the research. I could not afford to hire from a professional transcribing service and instead sent an email to a government secretarial site for people looking for extra work. The people I hired indicated to me that they were familiar with transcribing documents, which was verified through references. The transcribers were required to sign a confidentiality form, in which nothing concerning the interviews could be repeated, and that all copies of the transcript would be destroyed. The tapes that the transcribers received were ones where the interviewee specified on their informed consent forms that confidentiality was not a concern. In the end a hired transcriber transcribed eight interviews, and all were re-transcribed by myself to include more specific information about intonation, pauses and voice but primarily to include missing information, correct names and details. I also found that when reading the transcripts I had not interviewed it was more difficult for me to recall memories of the interview context

and I felt more detached from the text. In many respects this experience highlighted both the time consuming process of transcribing tapes, and the problems one might have from an outside transcriber who is not familiar with the interview in picking up on important detail and context of conversation.

3.5.2 Working with the transcripts and other textual material

In order to guide me through the process of analysis I looked for examples within the literature on methods of analysis and how these methods have been transformed and used within research practices but have found little to draw on. Much of what I have read has provided me with a strong theoretical underpinning but has left me unclear of how to translate those ideas into practice. Feminists for example have written on reflexivity, power, voice and authority in methodology but little attention has been given to these issues specifically in the data analysis stage of research (Mauthner and Doucet, 1998:121). I have found few journal articles or publications in general that have detailed the process of analysis. And while many of these publications seem to require some discussion of methodological analysis, they seem more a convention than an integrated part of the discussion.

This is reinforced within the writings of various geographers who argue that practices of interpretation are rarely discussed in final publications or written documents, leaving the impression that the qualitative material magically appeared to support arguments (Jackson, 2001; Crang, 2001). Mike Crang identifies three reasons for this. First, the process feels un-glamorous and clerical. Second, it is an area where many people feel insecure about the comments and scrutiny of other people over their work. And third, that without common standards there is no shield of accepted practice to hide behind (Crang, 2001:215). Analysis is an area of the research where we are arguably most open to criticism, as it is the portion of the research that is most directly visible in the text. It is well recognized in feminist scholarship that research contains biases and values, that knowledges are situated and that the production of knowledge must be acknowledged reflexively (Hekman, 1990; Stanley and Wise, 1993). Feminists have had to accept that there is no technique of analysis or methodological logic than can neutralize the social nature of interpretation. Feminist researchers can only try to explain "the grounds on which selective interpretations have been made by making explicit the processes of

decision making which produces the interpretation, and the logic of method on which these decisions are made” (Holland and Ramazanoglu, 1994:133). In this way interpretation is not a process of testing and searching for ‘truth’ it is about a process of exploration and thinking through the material to construct arguments (Ramazanoglu and Holland, 2002). However, reflexivity also requires a certain level of self-awareness and transparency on the part of the researcher that not every researcher may have of their own work.

According to Bailey et al. (1999) transparency of the research process is necessary in order to develop analytic criteria that are systematic. Systematic criteria and analytic techniques can practically and psychologically help to deal with large amounts of qualitative material (Crang, 2001). Some feminist sociologists have used the notion of a relational ontology to inform their method of transcript analysis and increase the transparency of the analytic process. Relational ontology focuses on selves in relation and selves in process. Thus the researcher and researched are viewed as embedded in a complex web of relations and environments (Tronto, 1993; Mackenzie and Stoljar, 2000). Instead of focusing on a particular method, the focus is on interpretations, understandings and versions of the method and of the transcripts (Mauthner and Doucet, 1998:126). This involves a reflexive approach to research where the researcher socially locates herself/himself in relation to the respondent. The researcher considers how one’s thoughts and feelings may affect one’s understandings, interpretation, and the way we write about people. And the researcher examines how theoretical interpretations of the interviewees’ narratives are constructed, simultaneously documenting these processes (Brown and Gilligan, 1992). This is a process of listening to the interviewee, which creates a space where we come to recognize the participants’ way of speaking and seeing as well as our own in order to understand how the interviewee speaks of him/herself before we speak about him/her. In this way it is important to hear other people’s voices as distinct from the researcher’s, and important for the researcher to continually come back to those voices during interpretation and analysis (Crang, 2001:229).

Data analysis is a critical stage in the research process because it carries with it the potential to amplify or decrease the volume of participants’ voices. The research process may be viewed as a balancing act between the multiple voices of our participants, the voice of the researcher and the voices and perspectives represented in the theories or

frameworks we use in the research (Mauthner and Doucet, 1998:140). One crucial question within the context of analysis is how to keep the interviewees' voices and perspectives alive, while at the same time recognizing the researcher's role in shaping the research process and product (Mauthner and Doucet, 1998: 119).

The early phases of analysis were messy, confusing and uncertain. For some feminist scholars this is the point of analysis, to learn from and about the data and to learn something new from listening to other people (Mauthner and Doucet, 1998:122). My process of interpretation began with rereading the transcripts. My resistance to computer coding for example has been a response to my interest in the tactility of the text. In analyzing data one is confronted with one's interviewees, and with their central role in shaping the outcome. This is enhanced through a continuous re-reading of the transcripts and journal entries in which one is confronted with the experience of the interview over and over rather than computer coding material where we are presented with selective segments of the interview which often seem fragmented from the interview as a whole (Mauthner and Doucet, 1998:122).

Re-reading the interview and my journal text, is a method of saturating oneself with the text, helping the researcher remember and re-enact the time and place of the interview. The process is slow moving in that it is a long drawn out process of re-reading and recalling, yet dynamic in the sense that new memories and connections are experienced with every consecutive reading. I kept anticipating some moment of revelation, where meaning would pop out from the text at me, but no such moment of immediate revelation occurred. Yet, reassuringly with each consecutive reading of the interviews I realized that there was a great deal of information in the transcripts that could be used, if not too much information.

In the process of analysis and interpretation of the narratives a variety of information is considered: verbal interview material, field notes, information received before and after the formal interview, informal meetings with interviewees, and non linguistic and non verbal information such as bodily and facial cues and pauses of breath. But the transcribed interviews on paper contain little of this information and as a result the analysis is informed less by these kinds of information. However, during the process of re-reading the transcripts and journal memories, impressions, settings and non-verbal cues of the

experience of each interview emerged and were noted down within the transcript text in a separate column. To help with this process, interview tapes were also listened to with the transcript text in hand.

Both the process of re-reading transcripts, journals and other material provided from the ADAO has helped to inform my analysis. Yet, I have always found the term ‘analysis’ less appropriate than ‘synthesis’ for the way in which I approach interviews because I am much more concerned with seeing connections within interview material and collaging these ideas together with broader theoretical discourses. Based on the readings, intuition, and my memories of the interviews I began with the code of ‘heart’, which led to the thematic identification of other embodied metaphors such as breath, then mind, then body. I first looked for examples of these words in the transcripts and then in the documents provided by the ADAO. Simultaneously I examined how particular words or themes overlapped, were repeated or contested by my interviewees as a form of discourse analysis. I then identified the contexts in which these words were used and the meanings given to those terms. I used those contextual meanings to create another set of codes. For example the term ‘heart’ was often used in the context of care and caring relationships, connectedness to other people, or alternatively used as a reference for the embodied experience of a panic attack. Thus, I created new codes such as “care” and “embodied experiences of panic, sensations of panic” that became more specific themes to be further analyzed. This process was repeated with each subsequent set of more specific codes under the headings of heart, breath, body, mind. These were the primary codes or themes of the thesis. These themes were subdivided into secondary themes for example heart-care, passion, panic, which were further divided into tertiary themes i.e. care - clinical care, lay experiences, personal, and so on. This process yielded a set of four folders that contained quotes and material from the transcripts and ADAO documents that elaborated on a specific theme or sub themes (see Appendix V for example). Essentially these four folders contained large numbers of sorted quotes under different headings, similar to what would be yielded through computer coding. All four folders were examined for overlaps in thematic content, and a separate fifth folder identified these wider themes that structure the thesis as a whole and included material from other theoretical and academic sources. The thematic coding and discourse analysis produced material that was then synthesized into a chapter outline. Mike Crang (2001) refers to this process as collage like, placing fragments in such a way that they disrupt the seamless process of making research in the

end product. Additionally while I write about my methods in a coherent, linear fashion, the process was often disjointed and interrupted.

Crang points out that interpretation around ‘coding’ and the fragmentation of material or possibility of material becoming de/recontextualised into new analytic frameworks is a methodological and ethical concern (Crang, 2001:228). The term coding can imply fitting material into pre-existing set of categories. However, the codes developed for this thesis did not preexist outside of the research material itself as these categories were largely derived from my intuitive responses to interviews and the interview material itself. From that specific material I then employed other theoretical frameworks around the categories of body, mind, heart and breath to expand on interviewees discussions in multiple and different ways. The theoretical material highlights tensions within the research process that help to subvert, challenge or expand those theoretical discourses rather than simply reconfirming them.

3.6 Question 5 - Writing up

The process of writing up the thesis has been a long and problematic one at times. The process needs to be understood as constitutive of the ‘field’, because during writing up periods we are still confronted with the presence of our research subjects and the forging of political objectives that cut across both time and space (Nast, 1994: 57). While writing up issues of confidentiality become most pressing, as it is in the writing that we most clearly expose our research subjects to public and private scrutiny. As per interviewees’ requests the names used within the thesis are pseudonyms, unless the interviewee stated otherwise.

There are various issues that are of importance to feminist researchers involved in the process of writing up. First, writing the research is a part of constructing and informing the researchers’ own identity. I am the research medium and common denominator that has remained “ both constant and in flux as the many facets of my life criss-cross, each containing the possibility of understanding what I am doing in a different way” (Birch, 1998:172). For many feminist scholars this is simply a form of navel gazing. Yet, Liz Stanley (1992) has suggested that rather than view an interest in researcher identity as

narcissistic, it is a research tool necessary to understand the “social within each individual” and that research itself is a relational process of social construction.

Second, Dorothy Smith (1989) raises an important issue for consideration within the process of writing our research. She states: “we have developed methods of working with women that are fully consultative and open, (yet) a moment comes after the talk has been inscribed as texts and become data when it must be worked up as sociology” (Smith, 1989:35). Writing up is a process in which large volumes of research material may be edited out or included within the final written product. Ultimately it is the researcher who chooses what material is included where the act of looking of summarizing another person’s words and placing the within a different context or meaning can be an act of objectification (Gilbert, 1994:94). It is the responsibility of the researcher that is engaged in a mutual respectful relationship not to use one’s own ideas and arguments to simplify the experiences of those researched. It is necessary to work against the appropriation of other voices and to resolve the research into neatly packed wholes, research which is continually in tension without pretending to achieve resolution (Stanley, 1997).

Inevitably feminists work within the tension of placing our reading and writing subjects outside of the experiences from which they start in the creating of a textual world, and our memories and everyday experiences of the subjects themselves. Thus, the language we use when we write may play a role in sustaining hierarchies of knowledge (Standing, 1998:186). There is a tension between the conventions and language of academia and the comprehensibility of that language for people outside of the academic community, our research participants in particular. This issue is central to feminist research that to claims to be about, by and for women who may not have a background in academic terminology. As a researcher I feel uncomfortable at the disjunction between my spoken voice and written academic text, as well as the contrasts between the words of interviewees and my academic writing. During the course of writing up I often cleaned up my own phrases, pauses, and mistakes to make the text appear more seamless but did not initially tidy the words of those I interviewed. This reinforced, to some extent, the difference between researcher and researched. I felt this was problematic, as did those I interviewed who received a copy of their transcript. Often researchers use our interviewees’ transcript material spoken as is, to make their words look more authentic, while our language from transcripts is continually re-edited, or made absent, within the text (Standing, 1998:192).

Beverly Skeggs has pointed out that often interviewees words are taken directly from transcript to made their words look more authentic, however it often results in making the interviewees look simple (Skeggs, 2000). "The ways in which we represent and interpret our interviewees' voices reinforces hierarchies of knowledge and power" (Standing, 1998:190). Thus I made a conscious effort to equally tidy up my interviewees' language as well, though I did not tidy up punctuation marks that would indicate pauses or speed of speech. Tidying up the transcripts also made the interviews as a whole more homogenous, which in many ways addressed issues of confidentiality, which was a concern for participants.

Third, while I enjoy working with the complex languages and abstractions of theoretical language, as a researcher I need to ask what impression does this leave for those we research, does it reinforce the detachment of the academic world from the everyday lives of the researched. Does the interpretation of the worlds and words of our interviewees into more complex and difficult language imply that as researchers we have a greater understanding than those who form the research. bell hooks suggests that the dichotomy between academic settings and the everyday lives of our participants is a false one because as researchers we make choices and choose our audiences, we choose whose voices to hear and whose to silence (hooks, 1989:78). We are in the privileged position of naming and representing other people's realities. Thus, in turning private issues into public concern and in giving our interviewees a voice in public arenas, we have to ask ourselves whether we are in fact appropriating their voices and experiences and further disempowering them by taking away their voice, or by not providing them with enough voice. An important question that arises then is how we might present our work in a way that grants the speaking interviewee interpretive respect without relinquishing our responsibility to provide our own interpretation of their experience (Gilbert, 1994:94). We have to acknowledge that as researchers we have the last word, final editorial control over the work and it is in this arena that we must ensure that our feminist politics, those of the community and conflicts between the two, are reflected in the final form of the research, whatever that form may take (Madge et al., 1997:108). In response to these questions a separate shorter document, like an executive summary, has been written for the ADAO and research subjects themselves. This document summarizes the work in ways and using language that highlights concerns and issues of direct relevance to the research subjects themselves.

3.7 Conclusion-Methodological considerations

Feminist methodological discourses reflect a tension between the idealization of reflexivity as a form of transparency, and concerns researchers have around issues of power relations, knowledge production and relational ethics. Gillian Rose (1997) and Geraldine Pratt (2000) pose a similar argument about how feminist geographers have embraced ideas of reflexivity without adequately problematising their own ability to be self reflexive. For Rose, many feminists are guilty of what she terms 'transparent reflexivity' a type of reflexivity in which self location serves the purpose of stabilizing interpretation and removing bias in order to uncover the truth (Pratt, 2000:641). I would argue further, along the lines of Rose's arguments, that not only is there a tendency to render the worlds of the subjects as coherent and transparent but, there is also a tendency to present our research processes as coherent, linear, and contained, particularly when the information and material collected within the research may be fragmented and complex. In other words, when we read about methodology we are often presented with a discussion of theory, methodological themes and methods that cohere into the 'object' of our research, into organized distinct themes, which may not reflect the everyday practices and experiences of doing that research. While feminists are attentive to the 'messiness' of the contexts that are being studied, this messiness is often not explored within our own research methodologies and methods. The information we did not collect, the interviews we did not get, the projects that went hopelessly wrong, and the bearing these silences, fissures and contradictions play in our research. Kay Anderson suggests that "an interview that fails to expose the distortions and conspires to mask the facts and feelings that did not fit...will miss an opportunity to document the experience that lies outside the boundaries of acceptability"(Anderson and Jack, 1991:11). I think the same can be said of methodology. Perhaps in not exploring the messiness of our own research, and by pretending that research is a seamless production of knowledge gathering and analysis we are missing an opportunity to explore aspects of research and methodology that may be crucial to the research. As researchers we draw attention to the processes involved in doing research (Skeggs, 1997:9). However we can do so in ways that keeps the researcher in a situation that resists resolution in order to act politically without pretending that resolution has come, to both stay honest and keep moving (Ferguson, 1991:338) what I term 'methodological irony'.

By 'methodological irony' I mean that as a researcher we explore the 'messiness' of our own research rather than pretending that our research is a seamless production of knowledge gathering and interpretation. The reader of this chapter may notice a tension between a discussion of the methodological process, which is structured somewhat linearly and my interest in methodological irony. However, I hope that the focus on various methodological questions and problems encountered throughout the research helps to show that the methodological process was far from seamless and linear. A semantic definition of irony involves saying one thing and meaning another, moving between the "unsaid that is nevertheless said" (Foucault 1972:110). From the point of view of the interpreter, "irony is an interpretive and intentional move: it is the making or inferring of meaning in addition to and different from what is stated, together with an attitude towards the said and the unsaid... irony is the intentional transmission of both information and evaluative attitude other than what is explicitly presented" (Hutcheon, 1994:11).

In feminist theory the power of irony is in its potential to destabilize. Sometimes this power is directly harnessed to oppositional and critical ends; sometimes it is a more indirect attempt to work through ideological contradictions and not let them resolve into coherent and thus potentially oppressive dogma (Hutcheon, 1994:31). As such, irony has been seen as "serious play", as both a "rhetorical strategy and a political method" that deconstructs and decenters patriarchal discourses (Haraway, 1990:191). Irony is said to work to change how people interpret meaning because it "springs from a recognition of the socially constructed self as arbitrary and that demands revision of values and conventions" (Walker, 1990:4). Irony becomes a means of critique, or resistance to claims to 'truth'. Like other feminists I have found irony to be a useful way of thinking about methodological concerns for a number of reasons. First, the scene of irony involves relations of power based in relations of communication. It unavoidably involves issues of exclusion and inclusion, intervention and evasion (Hutcheon, 1994:2). Second, irony also highlights, that like discourse, it cannot be conceived of a speech act outside of a broader political framework and to do so is to risk idealizing communication as a reciprocal, utopian exchange and thus minimizes the workings of power (Hutcheon, 1994:17). Irony happens because of discursive communities that already exist, it is these communities that provide the context for both the deployment and attribution of irony. Irony can also be

used to avoid “premature foreclosure... to give the benefit of the doubt by allowing (a text) to contain whatever doubts come to mind” (Culler, 1975:157 in Hutcheon, 1994:28).

What I find most useful and appropriate about methodological irony is in what Linda Hutcheon calls its evaluative ‘edge’. Irony can put people on edge- nervous about how to fix meaning securely and how to determine motivation (Hutcheon, 1994:37-38). I feel that this tension, or ‘edge’ is one of the defining characteristics of current feminist methodology, as described by Rose and Pratt above, with its emphasis on the relational, representation, responsibility and the reflexive.

One example of methodological irony found within this research project is a tension around being a ‘good’ feminist researcher. One of the central tenets of feminist research is that research should contribute to the empowerment of others and allow neglected voices to be heard. Other authors have suggested what point is there to research if not to aim to change the world around us. These authors raise important issues about the use and purpose of academic research and at the same time they respond to criticism of the frivolity of forms of qualitative feminist work (Smith, 2001). But I would argue, what is the purpose of doing research if the researcher does not gain some enjoyment from or within the process and why would that be considered a frivolous or narcissistic concern? It would be difficult for me to sustain my ability to do this research if it did not give me some pleasure and insight. Discussion of enjoyment of the research process is often absent or skimmed over in methodological writings perhaps because of a fear that the work will be considered frivolous, and thus the aspirations of the project will be seen as unethical or less than worthy. The lack of discussion of fun or play within academic process is endemic not just to feminist geography but cuts across the spectrum of the social sciences, as a way of distinguishing between what is and isn’t ‘serious’ relevant academic work. I conducted this research project, not only to raise awareness, but also because I enjoy doing this work (some of the time). If I were to ask my research subjects, is it okay if I take away something from this research, is it okay for me to learn something about myself in the process, do you think they would say no? I think many research participants assume that the researcher is getting something less than altruistic from any research project, career advancement, publications and so forth. It may not be the primary aim of research, but I think that in order to have a reflexive research process one must gain knowledge about oneself, a self that is necessarily in flux, fragmentary and relational. The

methodological process of a reflexive project is one where we deal with people who through their narratives allow us to get to know something about them, as well as gaining a sense of one's 'self.' As Shulamit Reinhartz argues the key methodological tool is the researcher herself and the multiple selves that are created within the research process (Reinhartz, 1997).

In the context of the thesis as a whole, the focus on feminist and feminist geographical methodologies should help the reader situate the research in the substantive chapters to come within the context of feminist and feminist geographical scholarship.

Chapter Four - Background chapter: A brief history of the ADAO

4.1 Introduction

The previous chapter explored methodological considerations that have directed the thesis, in this chapter we come to know more about one of those research subjects. While the methodological chapter highlighted the shifting relationships between researcher and individual research subjects, the ADAO, the organization itself, is also treated within this thesis as a primary research subject. This chapter provides more detail about this 'actor' in the research project; its history, writings, the programs it provides, and the people who come to shape its structure and mandate.

Since the time frame of the thesis interviews (2000-2001) and continued research on the ADAO (1999-2002) there have been changes both within and outside of the ADAO. However, the programs and services outlined in this chapter still exist as vital aspects of the organization. Some programs have become larger and some have decreased in size. Funding has improved in certain areas, while in others resources are still unavailable. The context of mental health service provision within Ottawa has also changed. Different people head up various service providers and funding protocols have shifted alongside a change in provincial and federal leadership. The relationship of the ADAO to other anxiety disorders association has changed, and the ADAO plays a larger role within federal service provision. In spite of these changes it is important to trace the history of the organization, and to situate this history in relation to other service providers within the city and within Canada.

The ADAO, previously the agoraphobia and peer volunteer association (APVA) was established 1997. It was created in response to the lack of service provision for people with panic and agoraphobia outside of an institutional or clinical care setting. Like many grassroots mental health communities and self-help groups the organizing intent of the ADAO was to provide an alternative and safe space free from the evaluation of a doctor-patient relationship. The ADAO is a self help, consumer based, grassroots "registered charity and non profit corporation dedicated to promoting public and professional sensitization and awareness as well as assisting the community with early identification, prevention and finding treatment for persistent anxiety conditions. Assistance is provided through support groups, educational material and classes, companion support referrals,

phone support, seminars and presentations” (ADAO, 2001a). The ADAO has initiated a range of new programs and services since 2000 notably its youth education program, but is best known for its volunteer companion program in which volunteers provide support and assistance to agoraphobic individuals in becoming more mobile, as well as a fourteen-week ‘anxiety, panic and avoidance behavior management’ educational program in which individuals learn to manage and educate themselves about their anxiety conditions (ADAO, 2001a).

4.2 Getting started – From the APVA to ADAO

The anxiety disorders association of Ontario is the longest running anxiety condition group within the city of Ottawa, and province of Ontario. It has been described as a registered charity, non-profit organization, self help group, sufferer led and based initiative, grassroots voluntary association, and community based group. First established as the agoraphobia and panic volunteer association (APVA) in April of 1996, the ADAO is the brainchild of Cheryl Driskell, its current executive director. Cheryl started the charity because of her own personal frustration in finding services for people who are agoraphobic and have panic. She contacted the Canadian mental health association (CMHA), a Canadian wide organization that assists individuals, organizations and practitioners with mental health issues, for personal help and was told that they had never worked with agoraphobics before. However, the CMHA was able to provide Cheryl with a volunteer, as part of their volunteer program. Cheryl was matched up with a female volunteer with over fifteen years of personal experience of agoraphobia herself. Based on that volunteer experience, as well as the experience of other agoraphobics, she developed a program to train volunteers for a volunteer companion program for agoraphobic individuals and sent it to the CMHA.

The CMHA was impressed by the document and distributed it within their association. The volunteer director and program coordinator of the CMHA at the time suggested that because Cheryl was addressing a need within the community that the CMHA was not, she should organize some group or agency herself and develop the volunteer companion program. They provided free photocopying, help with putting proposals together and connected Cheryl with three other people to help set up the APVA and the volunteer companion program. Of the group it was Cheryl who took on a leadership role and began

to train volunteers, in conjunction with the CMHA volunteer program for the volunteer companion program. She then assembled a board of directors from the initial group of trained volunteers, got the group incorporated as a charity and began to write material on agoraphobia and panic as there was demand for such material. Cheryl wrote various educational pamphlets, which later were used in the newsletters and became the basis for the ADAO's booklets and workbooks.

In its early stages the APVA was focused on developing the volunteer companion program for persons with agoraphobia and panic, however as the organization increased the APVA began to branch out into other areas of interest - developing various anxiety and panic management workshops, raising awareness of anxiety conditions through promotional materials, and constructing a quarterly newsletter for members. The APVA was also involved in promoting other services and programs for those with various anxiety conditions within the city such as support group meetings, a twelve-week program run out of the Royal Ottawa hospital, and a range of holistic therapies. The initial mission statement of the APVA was:

“To develop and maintain a volunteer program in Ottawa Carleton to assist those people who are living with agoraphobia and panic disorder and to educate their family, friends, and community at large about these conditions. In addition we provide referral information, phone support and continue to network with other community organizations and programs” (APVA, 1997a).

As the APVA increased in membership and prominence within the city its mandate was expanded to include more programs and services directed at persons with anxiety conditions, their families, the public school system, a wider public, and clinicians themselves. By 1999 the APVA's membership and program based had increased dramatically. Thus, a decision was made to change the name of the group from the agoraphobia and panic volunteer association to the anxiety disorders association of Ontario (ADAO) to reflect the diverse range of conditions its membership were presenting. The choice of name was a contentious one because at the time the APVA only serviced the Ottawa- Carleton region and its outlying areas and because of the use of the term disorders which was seen to be stigmatizing. However, because 'disorder' was the common clinical convention, it was agreed that a wider public and professional audience would recognize the name.

The change in name in January 1999 was accompanied by a consolidation of charitable non-profit status, change of organizational structure, change of office location, and a change in mandate. The mandate reflected a movement of the vision from a volunteer companion network to an organization with a variety of different services with a primary interest in public education and awareness:

“The ADAO is a registered charity and non profit corporation dedicated to promoting public and professional sensitization and awareness, as well as assisting the community with early identification, prevention, and finding treatment for persistent anxiety conditions. Assistance is provided through support groups, educational materials and classes, companion support, seminars and presentations. Our aim is to aid individuals in achieving and or maintaining personal wellness and independence” (ADAO,1999a:1).

The change from APVA to ADAO was formalized through the publication and dissemination of the ADAO booklet/educational guide, which is a brief introduction to the range and management of anxiety disorders and description of services and programs offered by the ADAO. The booklet was distributed widely for a small cost, often at information booths in shopping centers and increased the profile of the ADAO within the city. But the booklet had a caveat, which reflected criticism the association had received from various clinicians within the city about its authority and legitimacy to support anxiety ‘disorders’: “this booklet is intended to be solely for educational and informative purposes and in no way replaces medical and psychological support” (ADAO,1999a:1).

The name change was also accompanied by the introduction of a web site and a toll free North American phone number that has allowed a wider range of people free access to information about anxiety disorders and the ADAO itself. While the number of ‘hits’ the web site receives has not be recorded, the phone in and request of information statistics average from 380 to 600 calls per month and the bulk of the calls are from clients looking for information about volunteers and the various programs that are offered. Statistically the number of calls dramatically increases around the time that the ADAO is featured on television and radio.

Over time the ADAO has become savvier in areas of fund raising, raising public awareness about the organization itself and raising awareness about anxiety conditions more broadly. This has been translated into increased demand for the ADAO’s

informational services and programs. Thus in response to public need and demand the ADAO provides a wider range of services, initiatives, materials and programs. In addition to promotional materials, anxiety management workshops, the volunteer companion program and the newsletters, the ADAO also provides the following services and programs:

- Facilitated support groups
- Several anxiety and panic and lecture series
- Volunteer companion program
- Workshops
- Youth education program
- Local phone support and referral line
- Educational presentations for corporations and government departments
- Information, partner and volunteer manuals
- Awareness campaigns and information on the management, etiology and treatment of anxiety, panic and agoraphobia
- A community bulletin board of events, programs and services throughout the city.
- Train the trainer program
- Fourteen-week anxiety management program
- Workbooks
- Newsletters
- Website
- Toll-free phone line

When the APVA was started it had not anticipated that all of these programs and services would be offered, aside from the original plan of a volunteer companion program. In the original newsletter the 'five year plan' of the APVA is described. It includes maintaining and developing the volunteer companion program; the development of an educational program involving going into the schools to educate youth (12-14 years old), teachers and parents about anxiety, panic and phobias, information sessions for the community at large, self help tape program that is affordable, more newsletters, and a center for healing. Almost all of these goals would be ultimately realized by 2002.

4.3 Organizational structure

The structure of the APVA/ADAO has changed several times since 1996 up until 2001. The first form of organizational structure consisted of Cheryl and three other people who had responded to advertisements to volunteer for the APVA. Those three individuals had training from Cheryl and the CMHA. At that time, in 1997, there was no paid staff and

approximately thirty volunteer companions. Thus, Cheryl and the Board ran all of the office functions.

The second board was more formalized and was created very soon after the first in 1997. Cheryl became the president of the board and thus was responsible for executing board decisions. It was much larger in size consisting of two original members of the board, including Cheryl, and eight other men and women. These board members were selected because they were the first people to come out of training as volunteer companions from the volunteer program. The board was organized into specific roles and committees, and the board was responsible for directing the APVA's vision and programs. Committees were set up to focus on specific aspects of the APVA's function such as education, fundraising and clinical research. Various members were assigned roles such as treasurer, secretary, but Cheryl made the bulk of organizational decisions. Cheryl was also still responsible for organizing staff and the office as well as acting as an intermediary between the organization and its membership.

The third board reflected the growth in the APVA's program and member base. It coincides with the organization's name change and consolidation of charitable non-profit status in 1999. While Cheryl remained in her position as executive director, almost all of the seven board members were new. It was decided by board members that Cheryl should take on a different role from President of the board and act as an Executive Director whose role was to bring ideas and information to the board, which would deliberate, approve or reject suggestions. Thus she was responsible for managing the daily activities of the organization, managing staff, providing ideas to the board and executing the directives of the board. The president of the board was responsible for directing the decisions of the board and managing financial and budgetary details of the organization. The new board was smaller. It consisted of eight men and women in total, and two other individuals filled the position of president of the board at different times. Board members were still organized into specific roles such as treasurer, secretary, etc. and into various committees. The committees remained roughly the same with an increased focus on fund raising and education.

Since the APVA/ADAO started many board members have left, either for personal reasons or through disagreement. Yet most of those members still remain active with the association as volunteers to this day.

4.4 ADAO locations

Initially the headquarters of the APVA doubled as Cheryl's apartment. The apartment was both a functional office space and the site of board meetings. The office was an informal and personal place but unfortunately limited in space. Due to the location of the office Cheryl conducted most of the office business herself. The APVA phone information, emergency hot line and referral services were managed through the office in Cheryl's apartment. Because the APVA still did not have enough money to hire staff, Cheryl was responsible for fielding most phone calls and responding to questions (money that was raised at the time was used to cover office expenses and a small income for the executive director). This meant that phone calls and email were responded to quickly but not immediately. It also meant that the amount of work being done by the executive director was exhausting. This became problematic for the ADAO as certain members felt that the amount of work being done by the president (Cheryl) was detrimental to the organization and more importantly to her health. Later when funds became available the APVA was able to hire part time staff to assist with office work and staffing the phone lines.

In January 1999, the decision to move the office elsewhere was finally realized, largely due to an improved financial situation of large donations and sponsorship. The office was formally moved to the Bronson center, a large building that provides low rental rates for non-profit organizations. The new office, in contrast to the old office, had one large room for workshops and groups, and a very small room in back for the office. The new office was not as inviting as the old office space and has acoustical problems but it allowed for a wider variety of activities to occur on site. However as Cheryl, now executive director, was not able to work outside of her apartment, but still responsible for the management of ADAO programs and staff, the old office was still an important and well-used place for the ADAO. For example, general meetings and board meetings were still conducted from the old office space.

The location of the new office meant that staff had to be hired, or needed to volunteer, to run and manage the office, as Cheryl was not able to physically work in the new space. Due to lack of funding, part time staff were hired to work several days a week to answer calls, email and organize information. There was no one single person working in the office all the time. This resulted in a lack of coordination and the continued reliance of many staff members on Cheryl's authority before attempting a task. This meant that many people who phoned received an answering machine and would have to wait for a response, and probably meant that many more people phoned in for help without leaving a message. These problems were rectified later in the next year with the hiring of full time consistent staff for the office. Due to funding difficulties however in 2002, the ADAO had to relocate back to Cheryl's new apartment. However, consistent part-time staff work in the office, assisting the executive director with daily office tasks.

One of the goals of the APVA highlighted in the first newsletter was to establish a center for healing that offers a "body, mind and spirit approach to treating anxiety disorders and phobias" with subsidized costs and home support when necessary (APVA, 1997a). For the APVA/ADAO rooting the organization in a shared and common space was thought to help engender a sense and place for community that would be inclusive of the experiences and mobility of people with all sorts of anxiety disorders.

"Cheryl and I had an idea, our dream was to open like a little community center where we would have different kinds of services. At the ADAO we believe that any thing, any type of treatment is important, whether it is yoga, meditation, everything helps certain people. And to have a community center devoted to this where people could drop by and hear lectures and meet people that could talk to them about all these different techniques, and women could get together and meet and just talk, not just women but men too. To have that kind of community thing I think would be great. Not always having to resort to an emergency room. If only a corporation could donate a building, or give us rooms, it would be great. I know a lot of people with panic or agoraphobia cannot get somewhere, but if we had a bus service just for them, a mini van. For them its important they say ' I really need to get out I need to be with somebody right now' and we could go and pick them up and bring them there. They would interact with other people. I think it would be great. It would really help a lot. It would help them reach their goal because they feel isolated. Any organization that deals with panic and anxiety needs to deal with physical and emotional isolation. You have nobody to reach out to, and no place to reach out to. Some people they can barely pay their rent, there is nowhere for them to go, no way for them to get anywhere and of course they are going to feel isolated and alienated and crazy. I am thinking of someone with almost no income. Someone who has more income has more ability, more ways for them to get out of the isolation. People need to feel accepted and things need to be set up, so having

a building of the ADAO would be a big step forward in having a better community” (Alexis).

For the ADAO the dream of a community center is a vision of a diversity of perspectives and practitioners working for those with anxiety disorders. It is a safe space in which sufferers can come and get help, an inspirational place that encourages people who are agoraphobic to recreate their landscapes of fear, and engenders a sense of belonging necessarily for the well being of many sufferers who feel alienated and isolated.

Unfortunately, the goal of a center has still not been realized because of very limited funds, yet it remains an important motivating vision for the organization.

4.5 Fundraising

For the first several years the APVA had no government funding and relied solely on: donations; membership dues; fund-raising activities such as bingo, raffles, ‘bowlathons’, a golf tournament, garage and bake sales; the proceeds from anxiety and panic management workshops and some revenue from the twelve-week and the fourteen-week program. Funding has always been a central issue for the organization. The ADAO’s increased membership and popularity did not guarantee financial profits, and funding was still a pressing issue. Previous funding ventures, such as the bingo, dances and bake sales were providing a stable and consistent amount of money, but not a large amount. The ADAO received a number of sizeable donations that allowed them to print and publish the ADAO booklets and hire more staff. However what has been most influential in raising monies for the organization has been the fundraising committee.

A fundraising committee had been established back when the association was the APVA, but became more aggressive about fund-raising when the charity was incorporated as the ADAO. A charity golf tournament was held which increased the profile of the organization and introduced the association to a wider number of corporate sponsors, which resulted in corporate donations. The fundraising committee, and its chair in particular, were moving towards larger single events rather than smaller sporadic events, culminating in the charity ball event, which has been an annual event since 2000. The charity ball was set up as a costume masquerade ball, a theme appropriate for an organization of anxiety and panic sufferers, with meal, entertainment, speakers, and a silent auction. The masquerade ball was located in one of Ottawa’s most prestigious

locations, the Fairmont-Chateau Laurier, and was well attended by a very influential group of dignitaries, politicians and media as well as the general public. The event was widely enjoyed and raised a significant amount of money, less than expected though because of high output costs. In its second year the ball was sold out, and made more money from the event, attracting media personalities as masters of ceremonies and speakers. Since then the ADAO has hired a professional fund-raiser to help organize more events and media campaigns for funding. The ADAO recently has also managed to receive several government grants to support its youth educational programs.

4.6 Programs/services/campaigns

This section elaborates on several the programs and services the ADAO has offered.

4.6.1 The web site

The web site, which was awarded a web award, is a combination of information provided in the educational guide and the newsletters. It also has a chat room for people to discuss material on the site or about anxiety conditions more generally. The web site allows for easier public access to the ADAO, which is particularly useful for agoraphobic individuals and is used as a source of information.

4.6.2 The commercial

In order to raise public awareness about panic conditions and the ADAO itself, the ADAO created a commercial that was aired nationwide for a number of weeks. The commercial was part of a Canadian broadcasting corporation competition for non-profit organizations to convey a public service announcement using youth services that would get street kids to film the commercial. The ADAO's commercial focused on descriptions of what it is like to have a panic or anxiety attack using a diverse number of individuals from a range of races, ethnicities, gender, and ages. The message was that anyone and everyone can experience a panic attack at some point, and that many people who experience a panic attack may not have the words for what is happening to them, but if you experience these symptoms you may have had panic or anxiety and most importantly you are not alone in your experience. The commercial ended with the presentation of the ADAO's contact

numbers, which resulted in a massive surge of phone calls for the organization following the commercial from Canada and the United States.

4.6.3 The newsletters

The newsletter has had a varied distribution list, in 2002 there were 83 subscriptions to the newsletters, but in the past there have been more and more who have received copies of the newsletter without subscription. The first official newsletter of the APVA was distributed around June of 1997. The newsletters provide anecdotal information and more general information about anxiety, panic and agoraphobia. Up until 2002 there have been fourteen newsletters distributed, progressively the newsletters have become more formatted and professional in appearance, though the appearance and typeset of the newsletters change almost every new issue. The newsletters are an attempt to bridge together conventional clinical thought on anxiety conditions with more alternative health practices and spirituality. The newsletters, more than any other written documents, reflect the spirit of the APVA and its transformation into the ADAO and unlike some other informational writings is directed specifically for an audience of sufferers and their relations. But, as the newsletters progress there is more overlap in content between program material and the articles in the newsletters, which is still balanced by personal stories. There is also increased advertisement of community and ADAO services and fewer requests for volunteers, in spite of the ever-growing demand of volunteers for various programs now offered by the ADAO.

4.6.4 Support groups

By 1998 it was obvious to those at the APVA that there was a large demand for services and outlets for discussion and support for those with panic, anxiety and agoraphobia, as a result the support group and twelve week programs were established. The support group was based out of a local community center in the Hintonburg area. The support groups are generally facilitated by a person with social work or other professional training with first hand experience of anxiety or panic. The meetings were weekly and generally eight to fifteen persons show up every week and they have continued to this day. Additionally two locations outside of Ottawa, Morrisburg and London, have been created as ADAO support groups. While the meetings are directed by a support group facilitator, the issues

discussed are subject to the concerns of the members of the group, and the meetings are most often about sharing personal experiences and relaying tips to one another. The support groups are currently operating in a diverse range of locations across Ontario.

4.6.5 The volunteer companion program

The volunteer companion program is still central to the ADAO, and is the organizations longest running program. The program was the first of its kind in North America, and perhaps world wide, in offering home support services for severely agoraphobic individuals. The volunteer aims to assist and support the participant in accomplishing a variety of goals leading to experiencing the 'outside world'. The support that is required may vary from daily chores, social contact and companionship, outdoor excursions; or just conversation, but the volunteer is not meant to be a personal assistant who runs errands or acts as a personal slave. Initially the process of acquiring and training volunteers was informal. Because the APVA needed volunteers, anyone who volunteered would receive minimal screening and a one-day session at the APVA office trained by Cheryl herself, alternately Cheryl would send volunteers to the CMHA for a three-day training workshop on a variety of mental health ailments. As more persons volunteered, and as the demands for volunteers grew, the training process became more consolidated and extensive two full day sessions (9 hours class time).

A volunteer companion training manual was written which provides information for volunteers unfamiliar with anxiety, panic and agoraphobia, training exercises, the roles and responsibilities of a volunteer and ways of handling various situations. The volunteer matching program is adapted from the Canadian mental health association's guidelines for volunteer programs. The process begins with volunteer training, and then participants and volunteers complete applications and are asked to provide references that are checked. Once it has been established that a volunteer has 'enough' information, knowledge and understanding of panic and agoraphobia they are placed on a list and matched up with a participant based on: age, sex, skills, awareness, commonalities of interest and ability, geographic area, availability of vehicle, smoker or non smoker, individual needs and goals. When a match has been established, a profile of each individual is given to one another verbally and if issues arise then further assessment is done. If everything seems in order that the volunteer must make an introductory phone call, in which volunteer and

participant can negotiate a course of action. A first meeting will follow the phone call to further establish the companion relationship. After the first meeting a trial period of one month takes place, after the month period a review takes place and if the match is unsatisfactory for either person then the match will be discontinued and alternatives investigated. If the match is satisfactory then the volunteer is asked to remain an additional six months with the participants, at the end of which another formal review and assessment will take place and both participant and volunteer can decide whether or not to continue the match. Most of this process was supervised by Cheryl directly as well as other members of the APVA. Feedback was also mainly filtered through Cheryl. While there are records of feedback from the formal six-month review process, there is very little formal recording of the process of matching, or why various people were matched together. Even today the current volunteer coordinator does not have a formal 'codified' system for matching. The training occurred in the APVA's headquarters.

There has always been a lack of volunteers to meet the number of requests for matches. However, the program has always been viewed as highly successful overall. Most volunteers remain long term volunteers often taking on more than one participant over the course of volunteering, and many participants become volunteers as a result of their experience with the program. Both volunteers and participants have become board members and have sat on ADAO committees. The program still continues today and demand is greater than ever.

4.6.6 Fourteen-week program

Due to the success of a twelve-week program jointly set up by the APVA and Dr. Dave Erickson, a psychologist at the Royal Ottawa hospital the ADAO developed its own fourteen-week program. The twelve-week program was run by Dr. Erickson and two assistants of his, who videotaped the program. It focused on cognitive behavioral techniques to develop coping strategies to deal with panic and anxiety. Issues that were central to the course include: relaxation techniques, self-esteem issues, how to deal with a panic episode, how to work with uncomfortable body sensations, how to work with catastrophic thoughts, assertiveness sessions and goal setting.

The fourteen-week program, unlike the twelve-week program was run entirely by people hired by the ADAO. Two extra weeks were added for discussion of anger management and more focus on aspects of nutrition and breathing exercises (ADAO, 2002a). The first fourteen-week program in March 1998 was facilitated by an interviewee who describes the original program as being largely derived from lectures and exercises in a cognitive behavioral framework, a lot of homework but not a lot of room for facilitators to choose a variety of exercises to be done in class. The success of the fourteen-week program resulted in the expansion of the program to two at a time twice a year in 1999, and the formalization of structure through exercises and information in the *Anxiety, Panic and Avoidance-Behavior Management Workbook* (2002a). The later fourteen-week programs were also facilitated by a senior and junior facilitator, ideally one male and one female to reflect the various gendered issues and genders of the clients, practically this was only the case for several of the programs.

The interviewing of the facilitators, like the hiring and interviewing of all of the other ADAO staff, was done in pairs in the APVA/ADAO Office, or Cheryl's apartment. This was ironically rather anxiety provoking for most of the people interviewed because the majority of interviewees had experienced panic or anxiety and because each interviewee was positioned anxiously in competition with the other. It was later explained that the hiring committee was interested in observing the dynamic between people, as the program involved working with another facilitator, the committee wanted to observe first hand how potential interviewees relate to one another and work with one another as well. The training initially involved reading over the workbook, asking questions and then being brought right into the orientation process as a junior facilitator for a trial unpaid period. The facilitators all had some experience of counseling, and to aid the process a program coordinator was hired who had previously run many of the workshops in the seminar series on self esteem and assertiveness which was her area of interest and professional specialty. The program coordinator oversaw the training and management of the facilitators throughout the courses.

The workbook, which accompanies the fourteen-week program, was distributed to facilitators and clients was organized as a series of holistic chapters moving from (in weekly order): general information about what anxiety disorders are; to treatment, medication, nutrition and relaxation; to emotional well-being; automatic and catastrophic

thoughts, to core beliefs; exposure avoidance and goal setting; mindfulness techniques and coping strategies; effective communication, speaking and listening skills; self esteem issues; assertiveness training; anger management; and how to address various setbacks or awakenings (ADAO, 2002a:5-7). The workshops were well received and highly recommended by the clientele, but there were criticisms about the workbook and are currently being amended to reflect these criticisms. Eventually the workbook is slated for publication to be distributed more widely, similar to anxiety management and self- help workbooks such as Bourne's *The Anxiety and Phobia Workbook* (2000).

p until fall 2001, the fourteen-week program was fully booked and had a long waiting list, but with the development of the Royal Ottawa's anxiety workshop programs, the demand for the fourteen-week program has lessened, much to the disappointment of the ADAO.

4.6.7 Youth education program

One of the initial visions of the organization was to set up education and awareness programs for children and youth, and it is an idea that has been developing slowly since 1996. In fact the ADAO received a trillium grant from the Ontario government to help cover the costs of the youth education program. The focus on education of youth and children comes from the personal experiences of anxiety and panic in childhood by those who have organized the ADAO. The initial plan was to inform teachers and parents what can be done for children with anxiety and panic, and to give children the vocabulary to describe what is going on with them, thus, recognize what is happening to them, and perhaps change their core beliefs about those experiences. There have been a number of attempts to introduce these issues, through speakers and lesson plans within the public and roman catholic school system, and in 2000 the roman catholic school board allowed the ADAO to present speakers in class, while there are still administrative delays by the public school board and delays for finalizing a 10 week in class program for youth (ADAO, 2002c). The presentation and protocol for speakers revolves around the discussion of F.E.A.R steps and a youth screen play to be acted and read in class (ADAO, 2000b). F.E.A.R stands for: "feelings, how does one know they were frightened; expectations, how did they interpret that experience; attitudes, how one can reinterpret that experience; and rewards, positive affirmation" (ADAO, 2002b:1-2). The speaker not

only introduces to the students what anxiety conditions are, but the prevalence of these 'disorders' and the supportive message that those in the class who may have experienced a panic/anxiety condition are not alone and not abnormal. The protocol for an in-class ten session program expands on this message including sessions on relaxation, goal setting, core beliefs and thought patterns, self esteem issues, exposure and desensitization exercises; communication and assertiveness skills, nutrition and emotional responses (ADAO, 2002c). The youth screen play which is discussed in both the speaker session and 10 week program focuses on a girl who has a panic attack, what it feels like and how she proceeds to get information and help for treatment options (ADAO, 2001c). In all cases the message is a positive one, that one can live happily with anxiety conditions and that one can overcome these conditions as well.

The ADAO had focused on anxiety and panic for youth under eighteen years of age bracket previously on the web site and in newsletters. A number of booklets and pamphlets have also been published and distributed that provide information for students about stress and anxiety management, *A Parent's Guide: Youth and Anxiety* (2001d), a small pamphlet on helping to manage stress, anxiety and fear for young people, and a parent and teacher educational guide on the ADAO's: *Life Potential Program for Young People* (2001b).

4.6.8 Train the trainer program

The ADAO is also expanding its network of professionals and health service providers within the province. In September 2001 the ADAO offered its first 'anxiety, panic and avoidance behavior management training for trainers'. A program specifically offered for private practitioners and agencies who may need specific training for clients with anxiety conditions. The program reflects the initial spirit of the ADAO and its holistic philosophy that combines CBT, mindfulness practices, nutrition, relaxation, stress and anger management and assertiveness training. Through this program the ADAO has become a professional consultant, selling its fourteen-week program as a professional course for health service providers and practitioners, along with (sliding) professional membership fees and ongoing support and education by ADAO consultants.

4.7 The ADAO and the wider community - the context of mental health service provision in Ottawa.

The anxiety mental health service 'community' in Ottawa is dominated by clinical organizations, with the anxiety and mood disorders unit and pharmacologically oriented anxiety research unit (SACR) in the Royal Ottawa hospital (ROH) at its center. Within Ottawa an increasing number of private practices and private anxiety disorders clinics has emerged since 2000, as have the number of research centers based at the University of Ottawa that investigate anxiety disorders. Alongside these clinical practices are state based organizations, such as the Canadian mental health association (CMHA) and Canadian center for addiction and mental health (CCAMH), that attempt to bridge the link between public health and clinical institutions. CMHA and CCAMH also assist individuals and their families in connecting with existing mental health services and practitioners, act as patient advocates, provide the public with educational material of mental health issues, and inform the public what services are available for those with mental health problems. Since 2000 there has also emerged a range of non-clinical therapists and alternative non-western clinics and therapeutic programs that offer sufferer's different perspectives on anxiety conditions. In spite of the increase of clinical and non clinical services offered to those with anxiety conditions, the number of community based, voluntary, self help, consumer based groups that directly deal with anxiety conditions has decreased in large part due to financial setbacks. During the time of the research, 1999-2002, the ADAO, which is the longest standing voluntary organization in the city, was the only self help consumer based group in the city that focused on anxiety conditions.

In the landscape of service provision in Ottawa there are those within and outside of the clinic who do not think that clinical and non-clinical spaces should meet, or overlap one another, while there are some who would prefer that those spaces overlap. More often it is institutional (ROH) and bio-medical service providers who believe that there should be a clear division between the clinical and the non clinical, and within the clinical its own sub-divisions. For those service providers the non clinical should remain a separate sphere and place, though there is little differentiation between various community group services and alternative or 'complementary' clinical practices. There are those members of the ADAO

who want non-clinical practices to remain separate from the politics and problems they observe within the clinical health care system in Ottawa. Yet, most interviewees within the ADAO discussed the importance of networking amongst other service providers, expanding the range of services, both clinical and non-clinical, that the ADAO could offer in order for the ADAO to be seen as legitimate and important within the city and beyond. Thus, members of the ADAO were concerned to enter into a network of formal clinical landscapes of health care and overlap their functions and spaces with those of the 'clinic'.

The ADAO's relationship to other service providers within the city has been mixed. The ADAO has historically not had a productive relationship with biomedical service providers, and various private clinics that are more medically oriented. Yet the ADAO has a working relationship with the anxiety disorders unit at the Royal Ottawa and sits on one of its advisory committees. It has a good relationship with various clinical and non-clinical practitioners and has established itself within the governmental and social services sector where it is respected, referred to, and considered an effective, professional and credible organization. Since 2000 the ADAO has increased its partnerships with private professionals and academic researchers. The ADAO has also extended its network by partnering with other non-profit associations across Canada that address anxiety disorders such as the anxiety disorders association of Manitoba (ADAM), the anxiety disorders association of British Columbia (ADABC), and the newly formed anxiety disorders association of Canada (ADAC), where the ADAO has a member on the board of directors. These associations tend to be dominated by clinicians rather than consumers in staff and board positions, an organizational trend that the ADAO is also moving towards.

4.8 Conclusion

As discussed in the introduction and methodology it is important to do research and provide information about the ADAO whose experiences and histories have remained largely silenced, unacknowledged or subjugated within the health service sector and beyond. Conducting in-depth research on organizations that deal with anxiety conditions contributes to the aims of the thesis: first, to expand on the experiences of those with anxiety conditions suggesting the interconnectedness of individuals and groups for

meanings of anxiety; and second to constructively question the forms and effects of anxiety service provision for individuals and groups that deal with anxiety conditions.

This chapter has provided background information of the ADAO and its wider mental health context. The chapter has highlighted important aspects of the organizations history, structure, mandate and its current services and programs. The chapter has also elaborated on the relationship between the ADAO and other service providers within the city in order to further understand the context of mental health service provision. This chapter provides information that helps to construct new and critical questions about knowledge practices and power relations that are constitutive of the identities and communities that have shaped the ADAO in more precise and informed ways.

As a research subject the ADAO served as inspiration for the substantive chapter titles that follow - 'body', 'mind', 'heart', and 'breath'. These words and the metaphors they imply were used by interviewees to describe the organization, and were found throughout ADAO literatures. 'Body' and 'mind' represent particular tensions within the ADAO linked to body/mind dualisms, while 'breath' acts as a metaphor for the holistic nature and practices of the ADAO. The metaphor of 'heart' was most important and central in characterizing the ADAO by interviewees. For those interviewees without 'heart' the organization would have never lasted or persevered in spite of its difficulties and obstacles, described in this chapter. The substantive chapters that follow further unpack the difficulties, challenges and successes of the ADAO in order to address the question of how the ADAO attempts to balance its own desire to create its own unique place with its desire to be an active and integral part of the wider community.

Chapter Five – Body: ‘Imagining’ panic

5.1 Introduction

Our bodies are increasingly presented to us visually in ways that help construct representations and understandings about the self with direct implications for the construction of identity and community. The process of imagining oneself and one's body comes from a repertoire of images and imagery that constructs and shapes our bodies, subjectivities and identities; hence the term *imagining* (Van Dijck, 1998).

This chapter examines how the legacy of *imagining* mental illness affects individuals with panic and agoraphobia and looks at the meanings of those images for organizations such as the ADAO that aim to assist and to raise awareness about anxiety conditions including panic and agoraphobia.

The experience of panic illustrates how our bodies are *imagined* and have been affected by a genealogy of *imagining*. Largely invisible and undetectable by others, the panic experience is not marked by glaring external signs and symptoms and is often undetectable by medical apparatuses. Sufferers however, believe that others can see their panic, becoming hypersensitive and hyper-self aware of themselves. They fear that others will see them in an out of control, panicked state and assume that they are crazy. The resulting cycle of self-monitoring and avoidance behaviors stemmed in feelings of otherness, shame and alienation leads to less frequent public discussion. Which further results in a perpetuation of misunderstandings and misinformation about panic affecting sufferers and organizations seeking to increase awareness and educate the public about anxiety and panic conditions.

The task for organizations like the ADAO is to address the association of mental illness as madness, and to negotiate the invisibility of panic and other anxiety conditions within the public sphere. The experience of ‘being seen’ is connected to a politics of recognition and increased awareness. This chapter explores this tension between the visibility and invisibility of panic as a consequence of the legacy of *imagining*, and how it affects individuals and groups that deal with panic conditions.

This chapter examines issues of the 'body' that have become an important subject and object within social sciences and geographical discourses. This 'body craze' is rooted in critiques of mind/body dualisms that underlie the production of knowledge within the same context. It seeks to investigate the material and representational ways in which our geographies, subjectivities, identities and communities are negotiated and produced. The 'body' is discussed and the question of whether an examination of the body can help to achieve more emancipatory social and political relations in addressing issues of marginalization and social justice is touched on (Longhurst, 2001:5).

The chapter further demonstrates how an examination of the body offers a way of promoting new understandings of power, knowledge and social relationships between individuals, groups and geographies. In it a case is built for the importance of the 'visual' in the experience of panic and agoraphobia and the creation of specific 'mad' identities, subjectivities and geographies. Two sections, section 5.2 and 5.3, will analyze how the in/visibility of panic affects the daily-lived experiences of individuals with panic and agoraphobia and organizations that address those conditions. Section 5.2 introduces the experience of panic through the question - what is a panic attack? It then examines the genealogy of the visual within western medicine with a specific focus on the histories of hysteria that have informed the *imagining* of panic. Next comes a more thorough exploration of how the tension between the beliefs that illness can be read as a surface presentation of, or within the body. Section 5.2 addresses several questions that affect the lived realities of anxiety conditions such as panic, such as: why do people think panic is visible to others? What do sufferers imagine they look like to themselves and others? What effect does the legacy of imagining have on people with panic? And why are the fear of the hysterical, and the legacy of visualizing illness problematic for individuals? Section 5.3 focuses on the issues developed within section two in the context of the ADAO, related to why the tension between the in/invisibility of an ailment is problematic for organizations that address issues of panic. It offers some examples of how the ADAO has worked within a dominant scopic regime and negotiated the tension between the invisibility and visibility of panic. The chapter concludes by drawing together analysis within the chapter sections to elaborate on the connections between *imagining* and the healthy citizen. It does so in order to suggest

issues the ADAO must address in order to create a space that is inclusive of the lived realities of its membership, a place central to the ADAO's vision of inclusivity.

5.2 Embodying panic

5.2.1 What is a panic attack?

Panic 'disorder' is often described as a fear of fear itself, or as a fear of having a panic attack. Interviewees often describe panic in terms of mind and body and oscillate between the two in the experience of panic, simultaneously reinforcing and reconstructing a mind/body dualism.

"I think panic is a loss of control. It's a physical reaction and a mental reaction that, uh - I guess it's a mental reaction first which causes the physical reaction, and usually the physical reaction is not one that would be considered normal" (Sarah).

"I think I would describe panic as, uh, first of all, the, the physical sensation of having a panic attack so what that feels like, um, all the seen, the bodily sensations that you get from actually having it, and then it's the worry that, that, that constant worry, that interferes with your functioning on a day to day basis of, of when the next one is going to be. So it's really worrying about um, when am I going to experience that stage again. So it's really a state of heightened, heightened, heightened stress I guess would be the best example of what it sort of feels like to be in one. And then, the anticipatory anxiety that occurs in between the panic attacks I think is really, um, what, sort of how you know, that you have, I think that you suffer from a condition rather than an isolated event" (Amanda).

A panic attack is an important characteristic of panic conditions and a primary reason why individuals develop agoraphobic avoidance behaviors. Panic attacks are experienced in as many different ways as there are persons with panic, and are associated with a variety of fears, depending on the individual. Panic attacks are somatic sensations that are unexpected, that appear 'out of the blue' and include an overwhelming sense of fear and terror (ADAO, 2002a).

The physical sensations of a panic attack often resemble a heart attack. They are characterized by heart palpitations, increased heart rate, shortness of breath, numbing of various body parts, sweating, dizziness, faintness, hot or cold flashes, shaking or trembling, terror, fear of dying or losing control, and a sense that things either outside

or inside the body are unreal, to name a few (APA, 2000). The experience of panic and its pain shatters the self into a series of lived oppositions, therefore the fidelity of our bodies that characterize and ground our everyday functioning are substituted for a heightened sense of bodily *dysappearance* (Leder, 1990; 1992). This bodily dysappearance, in terms of a panic attack were often described by current and previous interviewees (Bankey, 1999; 2001) in terms of:

1) Depersonalization, the feeling that one is being dissociated or detached from one's body:

"I thought that people could see that I was losing control of my body, you know, that other people would see me as 'unreal, that I am fading away... but sometimes I think... what if people can see me panic and then I get paranoid and think I must look like I am going to scream, like everyone can see me fading out, screaming out of my body" (Lauren).

2) Derealization, the sensation that one is being detached, slipping away from one's environment:

"For instance I walk out of my door...The street would seem kind of foggy and the dark down the street looked so much further than it really was. The street would feel off kilter, you would feel unbalanced. Sometimes the road in front of the sidewalk would feel like it was dropping and your next step you were going down. The noises were louder and more profound and upsetting, petrol smells and that kind of thing got worse. Everything is intensified, except you're not, I couldn't tell you where I am" (Manon).

3) An increased awareness of external and internal sensations where the boundaries between self and environment are blurred:

"What happens to the space around me? I remember pretty much to notice what is happening in the moment when I am panicking. I'm thinking this is my environment and I will notice everything that's going on, and I will panic in that environment and try not to avoid the things I see and hear outside in order to avoid the things I feel in my body. As much as I am noticing everything, I have this shield going on, I don't want to be more focused on my body its scary, so I focus on what's going on in my world that I shouldn't be noticing, because its all too much, but I'm searching for something to distract me" (Nancy).

Derealization, depersonalization and the blurring of boundaries are all examples of the spatial expression of a panic attack, as the experience of panic is connected to the

spaces within the body, the production of landscapes outside the body, and the indistinguishability of the boundaries between those geographies. These spatial experiences also directly contribute to the development of agoraphobia, which is why according to the diagnostic and statistical manual (APA, 1994; 2000), agoraphobia is almost always seen by clinicians in conjunction with panic disorder, and 'rarely to never seen' without the onset of a panic attack. In this way panic is an important example of how the sensations and perceptions of our selves and our bodies affect how we understand the wider environments in which we are situated.

5.2.2 Why do sufferers think that panic attacks are 'visible'?

One central fear associated with having a panic attack is being seen in a panicky state. Individuals fear the physical experience of a panic attack. They also fear the thought that someone else might see them losing control and judge them to be crazy, mad or deviant. Individuals with panic think that others can see them having a panic attack because of a legacy of visualizing mental illness within clinical practices that has led people to believe that illness and madness can be read as a surface presentation of the body. The centrality of the visual within medical and clinical practices is based within a 'realist' positivistic perspective that focuses on observable 'facts' about the body as a way of understanding what that body is (Ussher, 1997:2). Here health and illness is measured through observation and visualization of bodily processes, what Gilman (1993; 1995; 1996) has described as the "primacy of the visual in western medicine" or the "medical gaze".

From this perspective comes the belief that mental illnesses are observable through and read on the body. The primacy of the visual in western medical and clinical practices has resulted in images of mental illness that have helped to define the meanings we ascribe to mental health- madness, deviance, abnormality - and that have helped create a preoccupation with how we look, how our bodies 'appear' to others and how we are thought of (Finklestein, 1991).

5.2.2.1 The genealogy of the 'gaze'

To understand how panic is imagined it is important to situate those images within a legacy of visualizing mental illness and illness more broadly. In *Naissance de la Clinique* (1963) Foucault introduces us to the “spatialization” of the body and the medical profession itself through the creation of medical landscapes mapped and inscribed on and within the body. These landscapes are created through ‘le regard de médecine’ that becomes translated in the English version, *The Birth of the Clinic*, as the medical “gaze” (1976: translator’s note). It is this gaze and the centrality of vision or seeing that gives meaning to our bodies while reinforcing the legitimacy of the medical profession’s authority to construct that meaning.

Sander Gilman expands on Foucault’s work on the gaze and its meaning for western medical cultures. The use of the image in medical history enabled the mass reading market to observe the physician at work. It not only enabled other professionals access to the body, but made parts of the body, and the body itself accessible to a much wider public (Gilman, 1995:13). Gilman argues that the history of western clinical practices, with specific reference to mental health issues, was organized primarily around the visual “dominant scopic regime” of the medical profession, itself derived from a long standing western medical tradition of representing the insane (Gilman, 1993:359). Observation has been used to identify medical problems in the body from the time of the ancient Greeks to contemporary western medical practice. Practitioners require observable symptoms to make a diagnosis or disease classification.

“To see the patient means to develop a technique for seeing, a technique that is scientific; the patient in turn, as the object of the medical gaze becomes a part of the process of the creation of the ontological representation of the disease...” (Gilman, 1993:353).

Thus clinical representations and images are situated within a “logic of visibility” (Chow, 1992), that is, techniques that privilege vision as a means of revealing ‘truths’ about the body, thereby assuming that illness and madness can be read as a surface presentation. This logic of visibility, or the ‘penetration’ of the medical gaze into the interior of the body in the practice of pathological anatomy, has been described by Foucault in *The Birth of the Clinic* as “the technique of the corpse” (Foucault, 1976). He notes that the opening up of the body in autopsy in hopes of exposing the origin of disease ultimately failed to render pathology fully visible, but led the physician instead

to map disease upon organs and surfaces, it became an exercise in the creation of new spaces for professional medical knowledges (Cartwright, 1995:xiii).

In the twentieth century, medical recording, viewing instruments and visual techniques have been crucial in the emergence of a distinctly modernist mode of representation in western scientific and public culture. A “mode geared to the temporal and spatial decomposition and reconfiguration of bodies as dynamic fields of action in need of regulation and control” (Cartwright, 1995:xi). Where medical textbooks and cadavers once replaced and provided a substitute for ‘real’ patients and ‘real’ specimens, new imaging technologies, health Internet sites, and Medical CD-ROMS now provide a “complex new reality of health and disease related to a new aesthetics of hyper reality and cyberspace - no longer is the static image the best reflection of the world of medical image making” (Gilman, 1995:174). Technologies such as the microscope, x-ray machines, ultrasounds, EEG, ECG, allow clinicians, patients and the general public to witness and animate the landscapes of their bodies and survey those spaces.

Donna Haraway talks about this in the context of the immune system, where the “dark recesses of the body become the domain of apparatuses of biomedical visualization” (Haraway, 1988:320). She describes how our insides are made comprehensible by the presentation of images of internal bodily processes. Thus the body becomes a frontier in which our own parts are seemingly being invaded by both “non selves that the immune system guards against but more fundamentally by our own strange selves” (Haraway, 1988:320). Twentieth century medicine does not so much ‘flay’ the body as it does away with distinctions of interior/exterior, object/ground; the body is rendered a part of a living system that incorporates technologies of its representation (Cartwright, 1995:xiv).

Biomedical apparatuses for visualizing the strange selves of the body have several implications for individuals and communities with anxiety conditions, specifically for panic conditions. They reinforce the credibility and reliance of biomedical approaches in the etiology, verification and treatment of panic. They also affirm the general belief that authenticity of experience is communicated visibly on and through the body.

People must be able to see what it feels like to have panic on the one hand, and on the other that if people can't see it, the pain cannot be that important a problem.

5.2.2.2 Vision, the body, and public health

The dominant scopic regime of medical practice has become central to established forms of medical and clinical practice, health promotion and public health care. Within current health promotional practices, techniques of seeing are transferred from the gaze of the clinician to the internalization of expert discourses that support constant self monitoring and vigilance in the maintenance of one's health and body (Petersen and Lupton, 1998). Public health practices are reliant on self-surveillance and on technologies of surveillance that permit the professional to verify to health of the subject.

Contemporary clinical discourses, such as public health, move the body from a passive receptacle of disease to a responsible and active agent of self-care (Lupton, 1995; Parr, 2002a). Self-care (connected to the self-care ethic developed in the next chapter) focuses on how bodily mechanisms, processes and internal images of 'our strange selves' are examples and emblematic of our bodies themselves (Haraway, 1988). Visualizing landscapes within our bodies require us to become fearful of our bodies and to maintain them vigilantly. A self-care ethic promoted through contemporary clinical and public health models does not produce an autonomous subject. Instead, it produces a citizen who is subjugated by professional discourses, technologies and representations of the body that become indistinguishable from the materiality of bodies themselves.

Current use of visual imagery and technologies of visualizing the body in public health practices emphasize that by seeing and identifying an ailment one is closer to self-care and cure. Bodies become a site of surveillance though the rise of visual public health information available through media forms such as television, radio, the Internet and the availability of pamphlets and written literatures (Parr, 2002a). Visual images of the body, fused with increasingly available medical expert knowledge, enable subjects to become "informed, technical actors in the creation of their body spaces" (Parr, 2002a:365). Individuals often fail to recognize that contemporary health practices lead them to adopt a carefully worked clinical script. These subjects of health promotion

discourse are not mere containers passively receiving information they are given instead they are seen as active agents in the consumption and production of self-defined healthy objectives (Brown and Duncan, 2000:265 in Parr, 2002a:365). Here individual body spaces are seen as complex sites of risk assessment (Lupton, 1999) that are 'worked on' by their owners to produce more sanctioned subjectivities, inscribed with medical and health knowledges that are appropriated and reworked by these "self made corporeal experts"(Parr, 2002a:365).

5.2.3 What do sufferers think panic looks like? Panic and Hysteria

When most interviewees described how they thought they looked during a panic attack they used images of hysteria, which carry connotations and representations of femininity and illegitimacy. In this way panic could be described as a fear of being thought of as hysterical - a fear of the hysterical woman. The dominant scopic regime of medical practice is clearly used in the history and imagery of hysteria. While the image of the hysteric may have changed, in terms of its acceptability and meaning, over the centuries the hysterical woman remains a powerful marker of mental illness. It is the predominant image of the body that interviewees with panic identified with, and is an image found throughout the ADAO writings (Showalter, 1997; Bronfen, 1998; Micale, 1995).

The image of the hysteric in the medical literature of the nineteenth century is an "essential image of deviance" associated with irrationality and ugliness, which are both highly gendered and sexualized (Porter, 2001; Gilman, 1993:362). These images present the hysterical woman as: dramatically writhing and possessed in convulsive, contorted "hystero-epilepsie" fits - often using images of other ailments, such as tetanus and epilepsy, to represent hysteria; bulging eyes and mouth wide open, nearly screaming, tearing at her clothes, often being observed by male onlookers; as the passively willing, fainting, patient of the master with no will of her own; or as a curved contorted body the frozen woman in an "arc en cercle" (arched back) position (Gilman, 1995; Bronfen, 1998:189).

This image allowed other physicians to readily identify hysterical symptoms and to identify overtly female sexuality as deviant, at the same time as it allowed the hysterical

woman to shape her identity according to this imagery (Gilman, 1993:367). These images of the hysteric always assume that there is a normal image of a productive healthy human, and that the deviant is marked by external signs (Gilman, 1995). The image of the hysterical woman is laden with implications of illegitimacy, inauthenticity and trickery, which translate into contemporary images and meanings of panic. Like hysteria, panic is often thought of as not being a 'real' or legitimate disorder worthy of much attention.

Two interviewees describe how they connected the experience of panic to a fear of the image of the hysterical. Both women acknowledged that panic cannot be and is not generally seen by others, the sense that panic can be read on the body is a strongly held belief structures the sufferer's sense of self. The private sensations of panic are translated into a public expression:

"[Sufferers] would say that they think everybody was staring at them, that everybody knows what's happening to them, maybe they're being laughed at, that there's just a sense that everything that's happening to them physically is, is for everyone to see" (Brittany).

Another interviewee elaborates by describing what happens during a panic attack but focuses on how those sensations are connected to what panic sufferers imagine other people think a person with panic looks like:

"Okay, well, I can tell you technically what happens, you start to feel fearful, so you get that feeling that I am in danger, I need to escape, because it is like, they feel as if there life is being threatened, so there adrenaline starts to go, the heart starts to pound, they start to breathe very shallowly, that makes them dizzy, you lose your ability to handle yourself properly because you don't feel strength, and then you become afraid that you are going to lose total control of yourself. Yet, because you are going to faint or you are going to collapse or your going to become hysterical, or have some kind of undesirable reaction in front of another person or people and that will cause them to judge you in a negative way. Then, I would expand that, panic, to what I think I look like, and I assume that's what other people see and there is a big thing that I look like... I imagine... I think I am going, they are going to see a weak individual who cannot control themselves and cannot handle a seemingly simple situation ...I guess maybe they would see someone who is bodily very emotionally, like a lot of emotions in the face" (Ashley).

Exploring the ways in which hysterical imagery is traced onto the contemporary beliefs about the experience of panic, illustrates how *imagenings* of mental disorder are traced and re-inscribed onto bodies, identities and subjectivities, and how these are translated into further representational practices. In exploring how those interviewed identify with the image of the hysterical I am also drawing upon histories that show how women and the feminine were and still are portrayed and labeled as deviant and irrational.

5.2.4 Panic and pain

A condition of the dominant scopic regime of medicine is the ability of an expert to see and measure illness. For any ailment to be authentic the pain associated with that illness must be measurable, quantifiable and observable. Pain like disease must be seen to be believed, authenticated, and confirmed. Telling the physician about the pain may result in diagnostic testing, but if those tests yield no observable results then the complaints of pain are not taken as seriously.

For interviewees both public spaces and spaces of professional medical consultation can become spaces of dismissal. The lack of noticeable symptom readings on biomedical apparatuses of visualization, or verifiable proof of panic reinforces the stigma that anxiety conditions are not 'real' problems:

"Number one, few people talk about panic if they suffer from it, and secondly, you don't look different, so anybody walking down the street that would look at you, they wouldn't have a clue what you were going through. I mean, you could be in the midst of a huge anxiety attack, and someone might not know it. Or, they [persons with panic] constantly go to the doctor and just say you know, I'm not feeling well, I don't know what's wrong and the doctor looks at you and says well you look great, there's nothing wrong with you, you know, your blood work is fine" (Madison).

This helps to compound sufferers' sense of distrust with their bodily sensations, and their own sense of insecurity about the authenticity of their complaints. While a panic attack is thought to be visible to others, the pain and the terror of panic is often not communicated or understood by other people. Since panic is not often recorded by medical devices, panic has not been considered a serious or even 'real' condition worthy of attention, research or sympathy.

The experience of panic is physically and emotionally painful. Meanings of pain, and our responses to it, are shaped by the medical gaze and biomedical imagery, which helps to authenticate our feelings and sensations (Shildrick and Price, 1998). In western medical regimes pain and visualization of (potential) pain are depicted as having a common motivational value that helps facilitate compliance to medical knowledge (Vasseleu, 1998:67). Biomedical images are used to transfer pain or emotion to an audience and in so doing fashion and construct responses to the meaning of pain and illness, of suffering and illness (Price and Shildrick, 1998:169). These images are also about the production of an individual who is capable of the surveillance and care of him or herself, an alteration of the embodied subject's relation to him/herself and his/her increased 'self care' through self-surveillance. This is not a process we undertake by ourselves, nor is the individual or group entirely active or passive in the configuration. The body of the clinical subject is never merely an object - its compliance is the object (Vasseleu, 1998:70).

Pain and chronic pain, in particular, is a betrayal of our fundamental trust of the body. "We feel under siege: untrusting, resentful of uncertainty and lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal" (Kleinman, 1988:44-45). Pain produces:

[A]lienation...being cut off from the outer world thrown back upon the body itself, in isolation, disintegration, pain...the unpleasantness of pain, the body and "I" instantly seem to have parted company...pain makes us believe that we can cut our self off from the body. Through rationalizing pain, my body and I become two separate entities" (Vrancken, 1989:442 in Williams and Bendelow, 1998:159).

When the pain of panic cannot be effectively communicated to others and believed to be real then individuals suffer the physically debilitating effects of a panic attack, and a profound sense of loneliness, isolation, stigmatization and dependence that often accompanies it. This loss of self becomes a fundamental form of suffering in which a 'painful' body emerges as an estranged, alien, thing like presence, separate from the self (Williams and Bendelow, 1998:160-161).

A problem for those with panic, or chronic pain, there are no cultural resources for organizing their experience because they cannot rely on the visibility of their ailment to inform a wider public:

“I think there are a number of issues, I think the first one is that it’s [panic and anxiety] not something which has readily identifiable characteristics its not clearly visible, so a you don’t know it exists unless you or somebody you know suffers from it and even then it is by its nature very difficult to understand... It’s called a mental condition that isn’t quite the right phrasing but its not an obvious physical condition, panic... it’s a physical condition, you are in a flight mode but that’s only visible to you, so its hard to recognize and even having recognized it, it’s even harder to understand” (Frank).

Sufferers often say that other sufferers are the only ones who can really understand their pain and audit their experience empathetically. This understanding however is often achieved through communication based on ‘communitas’ of mutual recognition and shared understanding of identity politics (Jackson, 1994 in Williams and Bendelow, 1998:163). The language of pain paradoxically becomes an anti-language - a kind of code and increasingly a rite of passage (Williams and Bendelow, 1998:163). When this language is told, its “‘lack’ becomes producing” (Frank, 1991) shifting the dominant cultural conception of illness away from passivity to activity (Frank, 1995). But those narratives of panic and illness still largely exist as private rather than public stories, and both private and public narratives are required for the painful panicked body to be understood and acknowledged.

Keeping pain private or expressing it publicly depends upon the context, beliefs and values of a particular group or individual and the ability for that individual or group to express it publicly (Williams and Bendelow, 1998:165). In the case of panic and agoraphobia the expression of the ‘disorder’ may have no accurate public face or outlet to draw upon or to begin with. For many of those with panic conditions, the pain-afflicted person may decide to conceal the experience of pain from potentially critical audiences if the social and emotional costs of disclosure outweigh the perceived benefits. The benefits of disclosure could include access to health care, sympathy and help in adjusting to effects of the pain. Experience may suggest that the costs of pain disclosure can be perceived as overwhelming. Certain reactions of critical audiences

may elicit feelings of shame and guilt which is common in the narratives of those with panic conditions (Kotarba 1983:134-35 in Williams and Bendelow, 1998:166).

5.2.5 Panic and shame

Because sufferers fear being seen in a state of panic, as hysterical, mad, or out of control, many hesitate to discuss their experiences of panic, contributing further to processes of otherness, shame and the development of agoraphobic avoidance behaviors. This contributes to the development of stereotypes of panic based upon the *imagining* of panic, caricatures of hysteria and mental illness, within various visual and print media. Images of panic are laden with stereotypes of femininity, fakery and madness leading to a cycle of self-deprecation, lack of self-trust and withdrawal. The alienation and privatized nature of panic and agoraphobia results from a loss of confidence in the body and a loss of confidence in the self, assisted through the reactions or lack of responses by others. Individuals feel isolated and ashamed of their panic so they do not create public discourses around panic that might increase public awareness of panic conditions. Many individuals develop agoraphobic avoidance behaviors and so the experience of panic is silenced and panic is relegated to the private spaces of individual experience.

The feelings of shame and guilt that are common in the narratives of those interviewed can be viewed as a process and product of a lack of discourse within the public about anxiety conditions such as panic and agoraphobia. For those I interviewed this was connected to the lack of visible signs of illness or pain in the experience of panic and agoraphobia resulting in its dismissal as a legitimate health concern, or completely ignored. For one interviewee panic and agoraphobia are beginning to be taken seriously but the single largest obstacle to awareness is that “when someone is having a panic attack you can’t tell, so it’s hard to be empathetic and understanding and supportive when there’s no outward signs. So often, I think it’s just missed” (Emily). This is repeated in another interviewee’s discussion of the politics of recognition of anxiety conditions more generally:

“I think the general public does not realize how intense the feelings are, if you have not experienced it, it’s hard to realize how intense it is, so unless they have

experienced it. I think depending on the individual if they are compassionate they can, I don't think they truly understand the extent of the feelings of terror that the person is experiencing" (Ashley).

Both of these interviewees are concerned with the development of empathy or sympathy in the politics of recognition, but invariably argue that the invisibility of pain in a panic attack works against the construction of a public discourse around the effects and consequences of their invisibility as examples of systemic discrimination. But making an ailment visible does not guarantee well being. The visibility of illness and impairment can be problematic when bodies are subject to mandatory regulated visibility and clinical surveillance. Thus, ailments are never a simply a private disease but always a public syndrome subject to a continual and all pervasive visual record (Nair, 2000:55). The bodies in these images are both an abstract conceptualization and a materialized effect, carrying with it the markers of racial, gendered, ethnic and sexual identity (Nair, 2000:56). As a discursive production these bodies are subject to what Arthur Kleinman describes as the "existential space between the immediate embodiment of disease as a physiological process, shown in the image, and its 'meaning laden character' that is created as a part of our experience" (Kleinman, 1988:56). This can be problematic as it creates both stereotypes and misrepresentations of experience that serve to dehumanize or objectify the self.

5.2.6 Summarizing the cycle of *imaging*

Both the body and images of the body in disorder are central to the construction of identity. The experiences of panic reconfigure a person's relationship between self and other, inside and outside, sound and sight, body and environment. But, while the resulting negotiation of spatial relations are dynamic and reveal much about perceptions and understanding of place and spatial practices, the spatial and somatic experiences of panic are not readily 'visible' by others. The sensations of panic cause the individual intense pain and fear that the sufferer feels must be visible. The person then associates their panic with imagery of madness and deviance that inform the panic sufferer's sense of self and boundaries. The person in panic often assumes, based on the legacy of the visual in medicine, that others see what they feel they look like and will realize that they have lost control, become hysterical, or that something is terribly wrong. But as most

people with panic come to realize their panic is not outwardly visible, and therefore their pain and suffering is not conveyed to others. This communicative barrier creates further problems for both individuals and communities that deal with agoraphobia and other panic conditions.

The belief that panic can be seen on the body as a marker of madness is a significant problem for those with panic conditions. The legacy of the medical gaze has resulted in the belief that if an ailment cannot be seen or read on the body then nothing is wrong. Yet, anxiety conditions such as panic are often not visible, either as an inscription on the body, or as something that can be read by a physician or by various other 'technologies' of the body (i.e. medical devices). This has resulted in the belief that panic is not an authentic or legitimate problem that does not require serious medical attention. This invisibility of panic fosters a sense of shame and otherness, both in the sense of feeling abnormal in relation to other people, and otherness in the sense of being invisible, of not being considered. The apparent invisibility of the ailment also results in a heightened need for self-monitoring strategies that can lead to further alienation and isolation from others in the form of agoraphobia. Additionally, the medical gaze helps to transform the nature of what is public and private in ways that are not necessarily enabling for those with panic conditions. In effect the medical gaze helps to create a docile body, subject to the expert discourses of clinical practitioners, and a body that is perceived to be even more unstable and untrustworthy without help and direction from clinicians. The legacy of imagening panic has become problematic for individuals with panic because it contributes to processes of othering the self.

5.3 Representing panic

5.3.1 Challenges faced by the ADAO

The way in which panic is *imagined* affects individuals' well-being and the ability of community groups and organizations to service and assist those persons. The ADAO faces several challenges in their attempts to help individuals and their families, educate the public and raise awareness about these conditions.

First, the ADAO needs to deal with the stereotypes of panic resulting from the legacy of *imagining* panic, as well as the popular usage of the term panic, as panicky. Second, the ADAO needs to raise awareness about the misperceptions of panic and dismantle these stereotypes without the use of an obvious visual referent as available images of panic are problematic. The experience of panic cannot be easily conveyed through a singular image. Additionally, many panic sufferers develop agoraphobic avoidance behaviors that make the 'face of panic' even more hidden from the purview of the wider public.

5.3.1.1 Stereotypes of panic

The lack of understanding about panic (because of a lack of visible imagery to communicate the experience of panic to a wider public) has perpetuated stereotypes about panic. These stereotypes have become the 'meaning laden character' of panic that further complicates an understanding of anxiety conditions by the general public - closely associated with the images of hysteria. One interviewee characterized 'public' perceptions and understandings of panic and agoraphobia:

"I think they wouldn't know. I absolutely think they wouldn't know. I think most people, um, if they do know anything about it, it's, it's - aside from people obviously that have family members and become educated through life...Anyone who's seen sort of a typical ER episode where they've got someone coming in screaming...I remember seeing once a woman who was screaming her head off, being brought in on a gurney having a panic attack. O.K., that's just not very realistic, most people having a panic attack no one even particularly notices. You know, and they are certainly not screaming" (Brittany).

Stereotyped images of hyper visibility contrast with the invisibility of panic in the public sphere and within the spaces of medical diagnosis and treatment. These stereotypes are further compounded by the development of language practices around the terms panic and anxiety. The word 'panicky' minimizes the severity of the experience of panic as a momentary product of nervousness, stress and fear that we can 'get over'. Both the general public and many academics have conflated panic with panicky, and thus have helped to sustain misconceptions about the experience of panic (Kroker & Kroker, 1991; Wilkinson, 2001).

We have all felt panicky or anxious at some point, but feeling panicky is not the same thing as a panic attack. In the absence of an image that conveys the embodied experience of panic, language practices have developed that represent panic in similar ways to the imagery and comical caricatures of mental illness and madness which highlight a lack of severity and non life threatening nature of mental disease (Porter, 2001).

“The label, the name, anxiety disorder, hey I have anxiety every time I go to make a presentation to a potential sponsor, I have anxiety every time we go into our selections, my athletes have anxiety every time they are in a starting gate, I don’t know if there is a better phrase. It’s a poor label if you are trying to create public awareness for it” (Frank).

The increasing presence of images of the body in panic based on stereotypes of hysteria, in the media, television in particular, frequently draw on simple caricatures of madness and hysteria. These images, largely ignored by public health and medical practices, reinforce the sense that our bodies are visualized and seen by others, heightening a sense of self scrutiny and self monitoring which reinforces the dominant scopic regime of the body (Lupton, 1999b).

5.3.2 Absence of representational form

5.3.2.1 Introduction

Anxiety conditions are the most pervasive form of mental ailment in western cultures. Invisibility of anxiety conditions within the public sphere creates specific agoraphobic geographies within the private sphere. A lack of accurate visual images of panic, and the prevalence of stereotypes that misrepresent the experience of anxiety conditions, lead to a lack of sympathy, interest and understanding of those conditions. This is one of the central concerns of the ADAO.

There is no simple way to explain panic to a wider public that highlights both the pain and severity of panic conditions. It is this lack of “visible messiness” (Longhurst, 1999; 2000; 2001), or the assumption that messiness is something visible on and through the body, that places many individuals and organizations that deal with panic at a disadvantage. They cannot rely on the visibility of an ailment to legitimize and further

their cause. The general absence of visible, biomedically measurable signs of panic means that it is hard to raise awareness about these conditions, no matter how painful or urgent the problem. This makes it hard to elicit a recognition of need within the public sphere.

Interviewees discussed the effects of the lack of visible messiness in terms of what the ADAO could use in awareness and educational campaigns. Section three explores issues identified by interviewees that may help lend credibility to organizations that deal with mental health issues. This section expands on the role of the poster child and the role of celebrity that interviewees identified as central to increasing awareness of health issues. The section concludes by offering counter models and ideas about the visual representation of mental health provided by the ADAO. These models may work within the language of the dominant scopic regime in which the body is scrutinized and understood, or they may offer an alternative way of thinking about the spaces of the body altogether.

5.3.3 Appealing to the public

5.3.3.1 The poster child

There is a need to create greater public awareness about panic conditions, such as agoraphobia, something that is central to the activities of most community-based groups such as the ADAO. Many other health awareness campaigns have converted the 'messiness' of bodies into streamlined objects of sympathy for the general public. Each image provides simultaneous, multiple meanings that the viewer accesses immediately and attempts to reduce to a single coherent meaning (Gilman, 1995:31). These images not only talk about the power and authority that are awarded to clinical expertise but they also show us how images that come from clinical practices are socially accepted and culturally dominating (Shildrik and Price, 1998:6).

The 'poster child' has become a convention of health awareness and funding campaigns in the late twentieth and twenty first century (Sturken and Cartwright, 2001). The poster child is a powerful image as Lauren Berlant describes: "the child's wounded image speaks a truth that subordinates narrative: s/he has not freely chosen her/his

exploitation” (Berlant, 2000:35). The poster child becomes an object of disavowal and fascination, the figure for the injured adult; it stands in for the traumatized virtuous private citizen (Berlant, 2000:38). The poster child of health is an image which is objectifying, in that the child becomes the sign/signifier of pain/death and thus stresses the urgency of need of care. But, it is also an image with whom we can connect to, as ill health or sickness is an experience that we all can relate to in some way, a reminder of our own imminent vulnerability and death (Porter, 2001). The poster child oscillates between pain as experience and pain as representation. As one interviewee describes: “an awareness campaign is successful because it’s been marketed well, it’s had a human face put on it. People are able to see that, that really could happen to me, or somebody I care about” (Stephanie).

Many of those I interviewed at the ADAO recognized the importance of a ‘poster child’, or a poster adult, for raising awareness and funding. One interviewee describes in this conversation some of the issues facing organization trying to raise awareness and the issues of identification that are necessary for effective communication of meanings of panic:

I think [panic and anxiety] ironically lacks from having a poster child. There are no obvious role models of people who suffer from anxiety disorder, so its hard to identify with it. If I’m a middle aged Canadian male and I start developing arthritis I can identify with Wayne Gretsky. I feel a lot better now, and I feel that there is a connection here, it is very, very difficult to develop that and by its nature it does not lend itself to that role model creating of awareness. So that’s one of the major things, also at the other end of using the use media, it’s a complex syndrome or issue to solve which is deadly if you are trying to go through the media, if you can’t explain it in 15 seconds you’ve lost them and this is pretty difficult to explain. So those are some of the challenges” (Frank)?

5.3.3.2 Mobilizing role models

In the previous excerpt the interviewee highlights the need not only for a poster child but a role model for panic and anxiety conditions more broadly. He suggests in further conversation that unlike the poster child that many adults can sympathize with and care for, people of varying ages need models they can identify, emphasize with and be inspired by. The role of celebrity and importance of celebrity identification and confessional was an issue mentioned by various other members of the ADAO. For one

interviewee, the seriousness of anxiety conditions is directly linked to the belief that “not enough people are known to have it, maybe nobody important (laughs) it seems to me” (Alexis). For another interviewee celebrity is an essential part of the politics of recognition and the development of sympathetic dialogue and role models within the public sphere.

“I haven’t seen any media representations of panic or agoraphobia so I don’t know, and off the top of my head I can’t, but there are quite a few celebrities that have come out and made a point of saying that they do suffer from panic and agoraphobia such as Kim Basinger...cause If you can relate to someone who has had it, and may have gotten over it, it might not seem as overwhelming... Celebrity confessionals are healthy, just for the fact that if someone in the spotlight admits to having something wrong, you might not feel so alone, as in so Kim Basinger has it, she has to do movies, she has to work, she had to make a living, and if she can overcome this, maybe I can do that, I am not in such a high demand or in the spotlight as such, and maybe I can do this, because my situation might be slightly easier than hers” (Amy).

The ADAO actively uses celebrity in their youth educational program and newsletters to show the wide variety of people who suffer from anxiety conditions. The celebrity confessional helps to both destabilize and reinforce the importance of illness or health being read on the body at the same time that it challenges the association between illness/madness and ugliness. Within western culture beauty and youth has been conflated with the healthy and normal body, while the aged, deviant/mad/ill body was characterized by its ugliness (Gilman, 1995; Porter, 2001). The association of celebrities, who are thought to be examples of beauty, with illnesses and mental diseases that are thought to exist in ugly bodies helps to shift public perceptions about that relationship (Finklestein, 1991). The celebrity shows through their own embodied presence that the appearance of a normal healthy body may not mean that person is free of illness or disease. The normal beautiful body as that which is absent of visible signs of pain and suffering reinforces the belief that - “I am healthy, because I look good, I might say that I am not feeling well, but at least I look good ” (Michelle). This image of health is the subject of cultural fantasies about the body in a particular culture- the theatrical function of illness and health is both an actor and frame of the action (Gilman, 1995:18). But, there are those who criticize the importance placed on the appearance of health and normality because through focusing on appearance very little is done to

substantively address the concerns and issues raised through illness experiences (Batt, 1998).

In spite of this criticism, the focus on the appearance of normality is very important in the campaigns for 'mental illnesses' in the hope of both de-stigmatizing previous representations of people with mental illness and of letting people who suffer from such ailments know that they are not alone in their experience and are not abnormal. It is this focus on the appearance of normality that predominates the imagery within ADAO booklets, pamphlets, youth and adult education and to an extent it is what motivates the ADAO's commercial. The appearance of the 'normal' healthy body; characterized by smiling faces, able bodies and a visible lack of panic, suffering or other markers of ill health on the body; are used by the ADAO to show that people who have anxiety conditions are "perfectly normal", like everyone else. The dominance of images of 'normal' in ADAO materials is significant. While it is impossible to accurately represent panic as a simple fifteen second sound or televisual bite, the ADAO's need to create images of the body absent of signs of ill health and pain reveals its willingness to adopt the dominant scopic regime and *imagenings* of the body.

5.3.4 Countering/displacing stereotypes

In spite of this, the ADAO has attempted to increase awareness of panic through a number of different educational programs. In this section of the chapter I focus on ways in which the ADAO has adopted, utilized and subverted both the *imagenings* of panic as well as the centrality of imagery and the visual within awareness campaigns. I describe the commercial made by the ADAO and how this visual presentation disrupts and utilizes the dominant scopic regime in which the body and clinical conditions have come to be understood. I also offer a different *imagening* of panic developed by the ADAO to suggest that the organization does have the ability and opportunity to move beyond the legacy of *imagening* mental illnesses.

5.3.4.1 The commercial

The ADAO commercial was part of a larger community scheme in Ottawa to provide teenagers an opportunity at television production. Community agencies would provide the material, scripts, actors and direction, while local teenagers would produce the commercial for the Canadian broadcasting corporation (CBC). Cheryl Driskell executive director of the ADAO wrote the script. In writing the commercial Cheryl had specific intents, representations and images that she wanted to include:

“Okay what I was trying to do when I wrote the script and got the people I wanted multi cultural, a different ages, so I had an aboriginal Canadian, I had an Asian Canadian, a black Canadian, a white Canadian I had a large Canadian, I had a small Canadian I had a young Canadian, I had an older Canadian, and a medium and a whatever, average person, I had them all in there and then I wanted to point out what does it feel like and where does happen because that will get people’s attention. Its not enough to go on line and say do you deal with an anxiety disorder blah, blah, blah, because people are going to go well what is an anxiety disorder? So what I did was presented a symptomatology, so I have one person say it happens in a crowd, in mall, in the middle of the night, well what happens, you now you’ve got their attention, and then it goes: my heart begins to race, I feel shaky, my legs go weak, I start to sweat, feel dizzy or whatever. And then people will go oh I have that. And then the commercial goes: if you are one of the millions of us who live with anxiety you can contact this agency blah, blah, blah, and the heart is beating in the background and it makes sense, because that is what got people’s attention” (Cheryl).

In this commercial inclusivity and commonality of experience was expressed through the presence of different sexed, ethnic and racialized bodies of different ages. In interviewing one of the actors in the commercial I asked him how he was briefed about the commercial and what message the commercial was trying to convey:

“Yes, the impression or the message. My understanding is that this disorder is not only limited to any particular group. One of the reasons why I was in the commercial was because I am a visible minority. This disorder is not only limited, kids, and people of different ages and I guess social groups and what not, and combined message, or at least I understood it off the bat” (Brian).

As Cheryl describes, the 30-second commercial consists of persons of various ages, gender, ethnicity and race who each speak a portion of the overall dialogue, though

certain words are said by the entire group. During the dialogue, in the background, the sound of a heartbeat gets louder and faster until the word “overwhelmed” is spoken. The commercial begins:

“It happens in a crowd... in class... in the middle of the night... in a crowd... when I leave my house... just out of the blue... my heart begins to race... I feel dizzy... My hands and feet go numb... Terror (said by the entire group) (image of an fearful eye, with pupil dilated) ... I feel fearful... helpless... alone... overwhelmed (group)... If you are one of the millions of us living with anxiety related problems take the first step to being fear free call us and get educated (disembodied male voice)”. This is followed by the ADAO’s website and phone numbers.

The commercial presents us with two interrelated discourses one which develops through the dialogue and another through the presentation of the actors and close ups to parts or expressions on their faces. The dialogue itself moves through a variety of spatial scales: time and environment, specific locations and times (or lack there of in the case of just out of the blue); the physical body and its sensations; the emotional body and its feelings. The spaces of panic described within the commercial are both within and outside of the physical body. There is a specific focus in the commercial on the word ‘terror’, which is not just said by all the actors but appears in bold type on the screen superimposed over a close up on a wide-eyed woman who looks fearful because her pupil is widely dilated and her eye is enlarged. It is this technical visualization of the widening eye that reinforces the legitimacy of the words spoken by the actors. We move between the dialogue to the bodily presence and cues of the actors in an attempt to bridge the dialogue with that image of fear represented not by the ‘normal’ looking actors but by the eye itself. The last section of the commercial’s dialogue seems to add an authoritative and clinical overtone to the commercial, through the disembodied male voice that provides the ADAO’s information and the lack of any actors.

The commercial, like many of the other pictures of persons used throughout ADAO materials, presents us with a variety of ‘normal’ looking bodies, reinforcing to both a wider public and to those who suffer from anxiety conditions that anxiety and panic sufferers are not abnormal, they come from every walk of life and are just like

everyone else (on the outside at least). The image of the eye is purposively disassociated from the body so as not to be identified with a specific actor because it might stigmatize or isolate that person from the other actors. The eye also acts as a signifier and embodiment of fear. One of the dilemmas for the ADAO has been the absence of any visual cues to provide visual representations of panic that can be understood by the public without panic; which is also why the commercial is primarily descriptive. In this respect the fearful eye is both suggestive of intense fear and panic that reflects the embodied experience how many people feel and look with panic, but is still reliant on visual bodily cues to convey a condition that is not visible to others.

“It [the commercial] was only 30 seconds long, and yet they had a huge impact because the drama was there, the darkness of anxiety. I wish they’d make a commercial about not primarily speech; it’s very descriptive. There are reasons why a descriptive format or describing have as opposed to a physical or more visual representation of panic or anxiety was chosen. Well, I would tell you from experience that anybody looking at it from panic and anxiety would not know. Most people if not all people around me when I was having severe panic and anxiety had no idea what I was going through, so visually it doesn’t mean a thing. You have to represent it at the core, and that’s exactly what you’re feeling, what you’re experiencing at the physical level, because it’s not visible” (Emily).

When I spoke with people informally outside of the ADAO about the commercial most of those I spoke to who had no experience of panic were still confused about what a panic attack is and its severity, while those who had experienced panic immediately connected with the commercial and its message, and found the commercial both inspiring and useful. As well the response to the commercial by persons with anxiety and panic conditions was evident in the tripling of phone calls from across Canada to the ADAO after the showing of the commercial. This reflects its target audience of potential clients for the ADAO, though according to the ED the commercial was meant for both a wider public and more targeted audience of client/consumers. However, there are differing opinions about who the target audience of the commercial is. For one interviewee it was:

“For the average population in general, because, it’s just because the profile of the actors involved in it its supposed to represent everybody...I would go back to the bottom message, which is it does affect everybody and if that’s the case, don’t feel that you are one of a kind, it’s a normal problem” (Brian).

Another interviewee felt similarly that “the commercial was addressing anybody who could identify with those symptoms, it was not limited to any age, color, race, it was multi ethnic, but defined by those symptoms” (Emma). While as some interviewees’ felt that the commercial was:

“Directed at people who have experience with panic and anxiety because that’s our [the ADAO’s] mandate; if it helps us to get a broad public, a commercial to involve other people, great but, I don’t think a general public would get it” (Emily):

Despite these differing opinions the commercial has had an effect both within the wider community and in attracting a community of potential sufferers. People with anxiety conditions across Canada responded to the commercial very positively, increasing the ADAO’s membership. Here the visibility of the ailment, through the use of images on television has contributed to a wider awareness of the organization and of panic.

5.3.4.2 Creating new *imagenings*

For those interviewed, both within and outside of the ADAO, the most successful image in conveying the severity of panic to those who have and have not experienced panic or an anxiety condition is an image which has little to do with the legacy of *imagening* panic. Alongside these images in the commercial the ADAO has also created images that help to convey to those who may not have had anxiety or panic, what a panic attack actually feels like. One of the most poignant allusions used by the ADAO, is the portrayal of panic in the car stuck on the train tracks, with the person unable to get out of the car and the train coming towards them. This is used in both the educational guide and youth educational program. It conjures up images, which can be understood by a broader public without first hand knowledge of panic, and be empathetically identified with:

“Imagine yourself in a car that has just stopped directly over a train track. You twist the key, on, off, on, off, but the car won’t start. The more you try, the more worried and frustrated you become. Suddenly you hear the distant sound of a train whistle and at that moment you start to sweat and your heart begins to race. You pull on the door handle and it’s stuck. The sound of the train is getting

louder. You're trapped and feeling completely out of control. The terror has begun. You move over to the passenger seat and desperately try to push it open. It won't budge! You jump into the back seat and continue to fight to get either door open. By now you're as white as snow and desperately trying to catch your breath. You don't know if you'll ever see your family again and you feel as though this is it, you're going to die" (ADAO Educational Guide, 2000a:5)!

The ADAO suggests that this image is useful for those who have not experienced panic and "have wondered how your family member, friend or colleague may feel when experiencing a panic attack" (ADAO Educational Guide, 2000a:5). The experience described is not a 'normal' experience in the sense that it is both unexpected and traumatic, yet it is a 'normal' everyday experience for many with anxiety conditions. It is an image that moves away from the space of the body and its visual presentation and instead focuses on the construction of a sense of place, empathetically placing the self within that physical and mental space. It is an image that suggests that the feelings of having a panic attack can be felt by any 'body', that anyone can place themselves in the car/train scenario and imagine the horrors of a panic attack. Here an entirely different language of experience is created. By moving away from the space of the body the ADAO constructs an image of panic that is not based in the legacy of the 'clinic', removed from existing stereotypes of the mad, deviant or disordered body and the dominant scopic regime of the clinic. The experience of panic is understood through the ability to empathetically enter into an imagined geography rather than through the creation of an imaginary geography of the body bound within mind/body dualisms and prevailing stereotypes of mental illness and panic. This image of panic, allows the ADAO to move beyond its dilemma of (in) visibility, and perhaps serves as a useful model for the kinds of images that are useful in promoting awareness and education of anxiety disorders.

5.4 Conclusion

This chapter is structured by the tension between the hyper visibility of the body felt by those with panic and the invisibility of this experience to others, resulting in a lack of public discussion and awareness of panic and agoraphobia. This tension is developed within the context of individual and organizational experiences. This chapter focuses on how the legacy of the visual still remains as a means by which information about mental

illness is conveyed, as well as, the struggles and repercussions of the *imagining* of panic for individuals and the ADAO. The chapter offers examples of how that legacy and the stereotypes that surround it can be reconfigured through the creation of a different set of sympathetic or empathetic images and spaces that are not based on existing *imagenings* of mental illness or madness. In this way the ADAO helps to create a new vocabulary of panic based much more in a geographical imagination than within the primacy of the medical gaze.

In connection to the wider themes of this thesis this chapter explored an aspect of the clinic and self care ethic that is necessary for its maintenance- the construction of a body that is made intelligible through visual monitoring and the 'gaze'. This contributes to the production of a body, and self, understood through continual self-surveillance and regulation. In this respect visibility becomes a component of the spatial reproduction of 'madness' and 'disorder'. These issues were explored through an analysis of how being (in)visible is a central problem and topic for the ADAO, how this has contributed to the organization's difficulties and the difficulties of much of its membership, both literally and metaphorically.

This chapter has highlighted how the healthy citizen is constructed on the basis of a particular type of body that 'appears' to be 'normal', where what is normal is both culturally defined and historically specific. To be a healthy citizen involves self-scrutiny of the body through constant monitoring of surveillance, subjecting the body the processes and mechanisms of surveillance that make both what is inside and outside of the body visible and readable. During these processes however, the body is often read in isolation from the person's life experiences, beliefs, values and social relations, and as such the body becomes objectified as an object of risk (Scott, 1999:134). The self monitoring process becomes a means towards making the body intelligible to others and to the self, but the healthy citizen is concerned primarily with maintaining an intelligible body that conforms to a particular set of standards or ideals. Once one attains that ideal or standard one becomes a healthy citizen. As Lupton argues the healthy citizen is directed towards the "development of a certain kind of mind/body relationship: All are directed at constructing and normalizing a certain kind of subject; a subject who is

autonomous, directed at self-improvement, self regulated and desirous of self knowledge" (Lupton, 1995:11 in Scott, 1999:138).

The experiences of anxiety disorders, such as panic and agoraphobia, form a 'body politics' from which we can derive different notions of subjectivity and citizenship. The experiences of anxiety disorders highlight how focusing on 'reading' and 'seeing' the body, does not necessarily lead to a better understanding of the body, or health and well being. In this way a 'body politics' should include experiences of the body as told or described to others- narratives of health, disorder and illness. It is these "stories of sickness" (Brody, 1988) that become the basis for understanding the body alongside other techniques that involve testing, measurement and visual assessment of the body. Within a model of health citizenship we move from the marked bodies of patients, of sufferers, of the disordered, knowledge based on existing norms, and the reading of the body by health care providers or by the self; to an embodied knowledge, that is knowledge grounded in bodily experience in specific materialities (Dyck, 2001a: 418). It is this knowledge that the ADAO needs to focus on through its programs, education and awareness campaigns to create further public discourse that is inclusive of the lived realities of anxiety conditions and thus foster the creation of a space for its membership that is its own.

Chapter Six – Mind: Governing panic

6.1 Introduction

As discussed in chapter two, anxiety conditions, panic in particular, are generally thought of and identified within the dominant discourse of clinical science as a mental disorder (Wilkinson, 2001). In this way panic always has some explanation connected to the 'mind'. By identifying anxiety conditions within the mind, persons with those conditions are subject to the stigma of mental illness. By stigma I refer to the portrayal of illness as a "one dimensional category of negative consequences and meanings" where loss of self and dependence on others supplants a positive sense of self (Barnes and Mercer, 1996:5 in Butler and Parr, 1999:5).

As developed in chapter five, 'body', the stigma of the mental is historically linked to images and beliefs about madness that have been used to help define whom or what behaviors can be considered normal, as well as, the kind of person or citizen we aspire to become. People with panic and agoraphobia often discuss how the stigma of the mental – the belief that an ailment is all in the mind and therefore not authentic- has a direct affect on how those people come to understand their bodies, themselves and others, as well as the places they live.

Mental health conditions are construed to undermine or even destroy the capacity of sufferers to look after, or govern, themselves appropriately. This is one reason why mental illness is so stigmatized. A consequence of the idea that those suffering from mental illness are incapable of governing themselves means that authority tends to be transferred to professional clinical experts. The privileging of clinical power and knowledge often results in the devaluing of non-clinical forms of knowledge such as the know-how of sufferers, identified as lay. This presents a self help organization for people suffering from mental health 'disorders', such as the ADAO, with significant dilemmas in terms of its ability to represent and address the concerns of its members.

This chapter examines how the stigmatization of anxiety conditions, in particular panic and agoraphobia, impacts sufferers' identities and affects the ADAO's organizational

development. The main analysis of this chapter is structured into four sections - from section two to five:

Section 6.2 is concerned with a theoretical discussion of mental illness and governing the self. The section begins with an analysis of the connections between the history of madness that underpins the stigma of the mental and regimes of governmentality. The section then focuses on a discussion of how processes of governmentality are implicated within public mental health care practices to help produce a particular form of moral selfhood or ethical subject. This process is described as a self care ethic.

Section 6.3 provides more details about how the stigma of the mental is embodied and experienced by those with panic conditions. This discussion is expanded within the section to help locate the geographies of fear in which that stigma is actualized and experienced.

Section 6.4 explores how the ADAO has addressed the stigma of the mental by becoming a more 'professional' and 'expert' oriented organization. This has meant that the ADAO has increasingly adopted more clinical expertise into its structure, mandate and programs at the expense of other forms of expertise.

Section 6.5 concludes the chapter on a different note from the rest of the chapter material by examining how the ADAO attempts to reclaim its capacity for self-authorization. This section is concerned with ways in which the ADAO resists forms of authority and meanings of expertise associated with professional clinical experts.

The chapter is concerned with meanings of expertise and professional knowledge. However, in this chapter the terms: 'professional', 'expert', 'clinical', and 'medical' are often used interchangeably by interviewees, which can be problematic as it suggests homogeneity of clinical practice that is inaccurate. Many clinicians would not claim to have their knowledge practices based in, or validated by, 'science' or would want to be lumped into one general category. However, the term clinical or clinician is used within this chapter as a reflection of interviewees' discussions.

6.2 Mental illness and self-government

6.2.1 Introduction

Historically madness and mental illness have been expressions of the human condition and expressions of the state of a particular society. However as the meaning and place of mental illness shifted from a social or public sphere to the private sphere of the individual madness ceased to become a reflection of societal problems and became an expression of lack of self-control, whereby the individual is in need of self-disciplinary practices and governance through clinical institutions (Porter, 1998).

“In our later modernity, our personalities, our subjectivities, our relationships with others, while considered private by most people are intensely governed, such that even aspects of the self deemed intimate and individual such as thoughts and feelings are socially organized and governed” (N Rose, 1992:1).

The shift in perceptions and the spaces of madness from society to self has meant that mental illness is directly implicated in ideas regarding personality (Richards, 1996:80). The stigma of the mental is a process by which meaning is ascribed to the body and self. It is part of the process of bringing the sufferer back, or pushing the sufferer further from, the boundary between normal and abnormal. It is part of the cultural process by which that boundary is continually revised and the meaning of madness and mental illness constantly reformulated. In this way madness has not only been used to help define whom or what behaviors can be considered normal, but the kind of citizen-subject to which we aspire.

If the citizen is marked by *his* rational mastery predicated on the centrality of *his* mind, then an unstable mind, signaled by mental illness is by definition an unstable citizen and unsuitable or unworthy person. Having a panic condition signals a character flaw in the individual and that the individual's capacity for self-governance and autonomy is undermined or diminished. Thus, forms of moral prescription and individual self-management- governmentality, care/practices of the self and the ethical subject- become more central to the development of the subject (Galvin, 2002). These three interconnected ideas- governmentality, care/practices of the self, and the ethical self - help to further explain the ways in which the stigmatization of mental illness have undermined sufferers beliefs in their capacity for self governance. Each will be explained in within this section.

6.2.2 Governmentality

The idea of governmentality originates with Foucault's work on the clinic. Understanding what Foucault means by the clinic is important in the context of this chapter and the thesis as a whole because the research is concerned with the relations between the ADAO and the 'clinic' as the clinic is central to anxiety service provision. The clinic refers to the dominant practices, discourses and knowledges (centered on the visual) that have helped to construct the institutions and understanding of medicine, psychiatry and other 'psy' disciplines as they are practiced today (Foucault, 1963, 1976). The clinic is linked to an ideal of democratizing "a general medical consciousness, diffused in space and time, open and mobile, linked to each individual existence, as well as to the collective life of the nation" (Foucault, 1976:31 in Philo, 2000:16). The term clinic is also important, because as Philo points out, Foucault's use of the clinic is not just about the practices of western medicine but about the spaces of western clinical enterprise. As Foucault writes in the preface of *The Birth of the Clinic* "this book is about space" (Foucault, 1976 in Philo, 2000). Thus the clinic involves exploring the actual spaces and places of clinical practice as well as the subjects and processes of subjectivity involved within those geographies.

Governmentality, a term used by Foucault and later used by a wide variety of theorists, can be explained as a kind of political technology in which practices and techniques align political objectives with the self governing capabilities of those individuals (Rose, 1992:147 in Galvin, 2002:122). Foucault's work on governmentality began with an exploration of the way in which expert knowledges are translated into "regimes of practice" thus institutionalized and spatialised in concrete forms of power and knowledge (Foucault, 1984). For Foucault governmentality is an explicitly spatial process that is extended into the structures and geographies of western culture (Philo, 1997). Governmentality involves a process in which space and place are interconnected to the knowledge practices of the clinical institutions and organizations. The privileging of expert, clinical forms of knowledge results in a spatial hierarchy that remains outside of the critical purview of a wider public yet is able to extend its influence into the public sphere (Foucault, 1975; 1977; 1980; 1984).

Governmentality incorporates an analysis of both the coercive and the non-coercive strategies that the state and other institutions urge on individuals for the sake of their own interests. It is a form of power that Foucault believes has dominated political and medical

power since the eighteenth century (Foucault, 1984; 1986a). The logic of governmentality entails that ‘the characteristic outcome of power isn’t a relationship of domination but the probability that the normalized subject will habitually obey (Johnson, 1993:142 in Lupton, 1995:10) Experts and their expertise are central to governmentality because in “modern societies power operates not so much through repression, violence, direct coercion or blatant control as through the creation of expert knowledges about human beings and societies, which serve to channel or constrain thinking and action” (Petersen and Lupton, 1998:xii). It is through processes of governmentality that expert knowledge is disseminated and internalized, producing particular versions of selfhood and the material environments and structures that (re) produce those subjectivities and identities (Foucault, 1984). Governmentality involves the construction of a subject through a web of expert judgments around the body; shaping conduct not through compulsion but through the power of truth and the potency of rationality and the alluring promises of affectivity (Miller and Rose, 1993:93 in Lupton, 1995:10). Governmentality is a diffuse array of power relations emerging from all areas of social life directed towards a plurality of specific aims (Foucault, 1984:95). While the clinic is important as a part of the structure of power relations, so too are the myriad of institutions, sites, social groups, and interconnections at the local level, i.e. the ADAO, whose concerns and activities may support, but often conflict with the imperatives of the clinic.

6.2.3 Practices of the self

In his later writings Foucault moved away from examining the external features of governmentality, those formulated and disseminated by institutions and agencies, to the autonomous modes of self government engaged in by the individual as part of everyday life (Lupton, 1995:12). He moved away from the geographies of external clinical structures to the relationship between those structures and the geographies and spatialization of the self and the body. Power operates diffusely and directly through investing bodies and populations with new capacities, especially the capacity for self-government (Petersen, 1996). This calls upon the individual to manage their own risk, using prescribed techniques and methods handed down through professional guidance, what Foucault has described as a “technology of the self”, “practice of the self” or “care of the self” (Foucault, 1980 in Shaw, 2002). In Foucault’s discussion of care however, unlike the feminist discourses on care examined in chapter two, the care relation invoked by Foucault is a subject/self one rather than a self/other relationship. By this I mean that

in his work on practices of the self he reflected on the processes by which the practices of the clinic and disciplinary power are internalized and embodied, seeking to explore the manner in which dominant discourses may be taken up, negotiated or resisted by individuals. Foucault became interested in the “ways in which individuals act on their bodies in order to attain certain states of happiness, purity, wisdom, perfection or immorality”(Foucault, 1988:18). For Foucault morality in particular is intimately connected to practices of the self. He used the phrase ‘ethical subject’ to describe how practices of the self are connected to emerging within moral action, and governing oneself morally. The ethical subject is:

“A process in which the individual delimits that part of himself [sic] that will form the object of his [sic] moral practice, defines his [sic] position relative to the precept he [sic] will follow, and decides on a certain mode of being that will serve as his [sic] moral worth”(Foucault, 1986b:109).

Emerging as an ethical subject requires understanding how various discourses assist us to avoid bad habits, conquer fears, and unlearn the past for the purpose of self-cultivation. However, Foucault was also interested in the possibilities that the ethical subject, and care of the self more broadly, presented for the development of modes of existence that broke with the normalizing tendencies in contemporary society, particularly the endless examination of one’s inner self which he saw as the dominant characteristic of modern society (Petersen and Lupton, 1998:10). Therefore, Foucault’s reflections on practices of the self suggests that although individuals constitute themselves as subjects in relation to external imperatives, there is a complex relationship between dominant norms, individual behaviors and actions, leaving much room for playful engagement with those norms and even resistance (Foucault, 1988:199).

6.2.4 The ‘self-care’ ethic

These aspects of the production of power: governmentality, practices of the self and the ethical subject have been extended into a system of clinical and public health promotional practices, of which the ADAO is a part, described as the “new public health” (Lupton, 1995; Petersen and Lupton, 1998). The new public health is based upon what I describe as a ‘self-care ethic’. The phrase refers to the tension between an understanding of health ‘care’ as that which is provided for us by others, and as that which we are responsible for. This self-care ethic is central to the creation of the healthy

citizen and provides a means of understanding the social and political roles of public health and health promotional discourses and practices (Petersen and Lupton, 1998). As Lupton and Petersen describe the term public health includes within it an assumption that members of the public are citizens, or will become citizens through the exercise of health. This healthy citizen, as s/he is represented in public health discourses emphasizes both the rights and the obligations of individuals to take up and conform to the imperatives of expert public knowledges (Petersen and Lupton, 1998:61).

The self-care ethic highlights how practices of health are imbricated in an individual's sense of citizenship because citizenship is embodied. As Foucault notes relations of 'power' in health care practices do not exist independently of the body, and are not external to the self: "nothing is more material, physical and corporeal than the exercise of power" (Foucault, 1980:57-8). Subjectivity, and processes of subjectivity are constructed through and by the articulation of power as 'one of the prime effects of power is that certain bodies, certain gestures, certain discourses, certain desires, come to be identified and constituted as individuals' and healthy citizens (Foucault, 1989b:98 in Lupton, 1995:7). This is identified by Foucault as "biopower", or the ways in which power relations work in and through the human body (Foucault, 1991). This is exercised through interpersonal relations in the clinical encounter and through disciplinary power of the body politic (Lupton, 1995:6).

With the growing emphasis on health as a personal strategy of self-care and resource for self-development, the pursuit of good health is considered both an obligation and a right of the healthy citizen (Petersen and Lupton, 1998:64). Good health is required for people to become healthy citizens because ill health removes individuals from the workforce and other responsibilities and places an economic (or social) burden on others. In contemporary health care systems the right to health involves taking on personal responsibilities for one's health by accepting that there is an imperative, ethic or duty to stay well (Petersen and Lupton, 1998:65). Individuals can express their ethical selves and fulfill their responsibilities as good citizens by managing their relationship to health risks (Lupton, 1999).

What differentiates the new public health from older health care systems is how the subject aligns personal satisfaction with the public good (Petersen and Lupton, 1998:70). The individual needs to consider what one can do to protect his/her own health and the

health of others (Petersen and Lupton, 1998:ix). However this consideration for others is structured by the imperatives of the clinic created through expert discourse and professional knowledge. The institution of public health, and a self care ethic that accompanies it, has served as a network of expert advice that have strongly coercive elements that set out to shape and normalize human behaviors in ways that are often not recognized as coercive because they appeal to widely accepted norms and practices (Turner, 1987; 1994). Within public health discourses individuals are obliged to take up and conform to the imperatives of expert public knowledges. (Petersen and Lupton, 1998:61) Personal choice is choice in as much as the options available are aligned with the objectives of the clinic and other social authorities and institutions (Miller and Rose, 1993 in Petersen and Lupton, 1998:63).

Health professionals within the new public health are less likely than they once were to directly intervene in people's lives in top-down efforts, instead they seek to assist subjects to develop their own capacities through detailed work on the self (Petersen, 1996:164). Thus, expert advice can be viewed as a process of consumption in which the individual is directed by expert power/knowledge to re-create themselves in ways guided and bounded by the professional (Kangas, 2001; 2002; Shaw, 2002). Individuals are supposed to continually interrogate themselves in the quest for self-improvement. Here, subjectivity is created through techniques of governmental self formation that are affected by external authorities and agencies and by practices of ethical self formation where individuals come to know themselves and give meanings to their experiences (Foucault, 1984).

Hence the creation of public health communities and groups that address public health concerns are central to the maintenance of the healthy citizen. These groups have the ability to highlight the connections between individual and group health issues. They also help mediate relations of clinical power, adopting wider clinical beliefs within a language and structure of lay knowledges. These groups can act both as mediums for forms of governmentality, or alternatively, and often simultaneously as forms of resistance to governmental structures and practices. This chapter highlights how the ADAO adopts forms of the new public health and self care ethic as it aspires to be viewed as an organization with the professional credibility to affect and direct change in people's lives, such that those people feel that they are the one's creating the change. Yet, additionally the chapter also offers ways in which the ADAO resists forms of, and particular discourses on, governmentality.

6.3 The stigma of panic

The stigma of the mental, the belief that an ailment is “all in the mind”, (Davidson, 2003) has become a marker of western culture, behavioral norms and geographies of fear and disorder. The stigmatization of mental illness comes to affect how people understand themselves, others around them, and the worlds in which they live. It is a stigma of associated with the spaces of institutionalization marked by the presence of the mad or mentally ill. These landscapes are imagined to be places of deviance to be avoided, feared and isolated (Gleeson and Kearns, 2001; Philo, 1997; Tuan, 1978). Drawing on material from chapter five ‘body’, the stigma of the mental is also associated with images of madness, what some interviewees described as the “mental health look”. Thus the stigma of the mental affects processes of identity and subjectivity focusing on the body and self as an imagined geography. The mental health look is associated with persons who are ‘out of place’ within the public sphere and are therefore discouraged to enter or are excluded from public spaces unless properly controlled, disciplined or surveyed.

“Imagine a panicky person is always panicking can’t do anything, not functional, looks funny, looks crazy, going nuts” (Hannah).

“Representations of people losing it, totally, of going ballistic and picking up guns and hurting people or smashing things” (Beth).

“Images of the stereotyped schizophrenic who talks to him/herself and has violent outbursts... images of the “homeless, alcoholic, heavily medicated” (Olivia).

Anxiety disorders, in particular panic and agoraphobia are intimately connected to feelings that one is going crazy, losing one’s mind, otherness, abnormality, is a sign of personal weakness, or lack of self control associated with madness and mental illness (Bankey, 2001). Interviewees’ discussion of panic as a mental condition was couched in a language of embarrassment, negativity, shame and otherness.

“People have fearful assumptions about different emotional and mental conditions and that, you know, if you have a quote unquote disorder, a mental disorder, then you’re you know, you’re crazy and you should be hospitalized, and you’re non functioning and all of that kind of stuff, that even people that don’t suffer from anxiety fear” (Brittany).

These views on mental illness are complicated, first, by the way in which mental health issues are often reduced to individual character flaws:

“I think before panic was, its all in our head, something is wrong with you. If it’s something like cancer or MS or a broken leg, oh you poor thing. But, if it’s something mental then they automatically assume that there is something wrong with you” (Samantha).

And, second, because of a disbelief of the seriousness or legitimacy of an ailment:

“There are probably a lot of people out there who feel just shake it off, and move on. Um, whether it’s family members, friends, just people in the community, um, employers, um, there’s nothing to be scared of, there’s no reason for you to panic, shake it off and let’s go” (Elizabeth).

The belief that panic is a sign of personal weakness, something that one can just “get over” produces a sense of shame that results in a lack of communication about their experiences to others:

“In our society mental health issues have not been regarded as politically and historically important. It has always been well it’s in your mind, don’t worry about it, well you will get over it. It’s something that in order to feel comfortable and not be shamed about, it, then you have to say I am not telling anybody and this is the way that I am comfortable... or you have to say I am going to avoid everybody and this is how I am comfortable” (Amy).

The stigma of having a mental ‘disorder’ also contributes to processes of alienation that lead to the development of agoraphobic avoidance behaviors:

“You question your own sanity. Uh, you know you’re trying to think, well, what is really wrong with me, and I think the whole fear factor and the isolation can leave you feeling very lonely and you know, withdrawn from the outside world, metaphorically and literally” (Madison).

The stigma of the mental involves fears that others will judge the panic sufferer to be crazy, abnormal or deviant, which is why persons with panic attempt to avoid the places in which they may have a panic attack, or be seen in a state of panic. These avoidance behaviors perpetuate a cycle of fear, shame, otherness, and dependency that often creates more problems for the individual. The restricted spatial mobility of those who are agoraphobic means that many of those individuals cannot do the daily activities they used to. Not only is there shame around being thought of as crazy, but interviewees described

the embarrassment agoraphobics feel about needing help from others and not being able to act normally, that is, independently.

“There is a lot of shame around just the things that they can’t do, right? Which they perceive as very problematic because they are the things that everybody can, everybody else can do... the social norms that everybody is involved in” (Amanda).

In summation, the stigmatization of mental illness causes many people with panic, including those interviewed, to feel that they cannot trust themselves, their bodies or their judgment. As a result those individuals tend to believe they cannot help themselves and need to get expert or professional help. As the tendency of clinical institutions is to value certainty over reflexivity (Beck, 1998) there is a belief amongst the public and patients that the authoritative advice given within institutions by experts is more trustworthy and dependable than their own (Philo, 1997:75). These institutions offer sufferers advice, direction and explanation in an authoritative expert manner, which helps to reassure the sufferer who is wary of his or her sense of self. The demystification of mental illness offered by governmental forms of clinical practice is grounded in scientific rationale and the importance of evidence and classification that involves a preoccupation with diagnosis, sorting and labeling (Philo, 1997:71). Professional institutions and the role of experts are characterized by an absence of self-criticism and constructed certitude, in contrast to the experience of a panic sufferer who is plagued with self-doubt and self-criticism (Beck, 1992). Clinical institutions and experts are an expression and image of the modernist belief in the power of science and expertise to solve problems, reinforce professional dominance and facilitate the search for technical-rational solutions to complex problems (Petersen, 1996:157). In this way we can understand how an individual struggling with their sense of self and bodily reactions, as well as, a group trying to gain credibility within a larger system that values scientific facts would move towards institutions that claim certainty over reflexivity and move towards the professional away from a personal ‘lay’ perspective.

6.4 Expertise and the ‘professional’

6.4.1 Introduction

The stigmatization of mental illness not only affects sufferers' perceptions of themselves, but the ability of sufferer-led organizations to gain credibility and acceptance within a public health care system. Because the wider public tends to view institutions of the clinic as the sites of primary health care many members of the ADAO want to share in the authority of clinical institutions that adopt hegemonic forms of care and clinical knowledge (Busfield, 2000). However, in doing so the ADAO devalues of forms of care that privilege non-expert experiences and knowledges that have historically been central in defining the ADAO's 'community' and its vision.

Within the landscape of anxiety service provision in Ottawa there are those, within and outside of the ADAO, who do not think that clinical and non-clinical spaces should meet or overlap one another, while there are some who would prefer that those spaces overlap.

"I've also picked up in the wind that there is a power struggle between the medical profession and the ADAO in a sense of uh, you shouldn't be doing this, because this is I don't know, we've classified the problem, so you can't touch it because you don't know what to do with it" (Chris).

More often it is institutional and bio-medical service providers who believe that there should be a clear division between the clinical and the non clinical, and within the clinical its own subdivisions. There are also members of the ADAO who want non-clinical practices to remain separate from the politics and problems they observe within the clinical health care system in Ottawa. Yet, most interviewees discussed the importance of networking with other service providers, expanding the range of services, both clinical and non-clinical, that the ADAO could offer in order for the ADAO to be seen as legitimate and important within the city and beyond. For many interviewees it is important that the ADAO establish itself within a network of service providers in order to disseminate information about anxiety conditions, create effective awareness campaigns, and provide programs for those who are affected by anxiety conditions. Thus, members of the ADAO were concerned to enter into a network of formal clinical landscapes of health care and overlap their functions and spaces with those of the 'clinic'.

It is easier for the ADAO to network within a public health care system in which clinical structures are dominant if an organization incorporates forms of 'professionalism', associated with spaces of expertise and clinical knowledge practices,

into their structure and programming. It is important that the ADAO network with other service providers within the city because government funding for mental health care requires that clinical/professional organizations and institutions partner with non-expert initiatives located within the 'community'. Community, grassroots or non-clinical organizations cannot apply for government funding unless they are affiliated with an existing government funded program (Canadian mental health association), professional (university researcher, psychiatrist) or health care institution. This has meant that the sharing of knowledges within the mental health sector has become a requirement, but the extent to which knowledges are shared and what kinds of knowledges are produced as a result of this process helps us to see the dominance of expertise and clinical approaches in the Ottawa area.

6.4.2 The power of professionalism

According to many interviewees one of the struggles the ADAO faces in attracting attention, and getting its message out, lies in its status as a professional group. Being seen as professional is connected to an organizations ability to raise awareness, attract the public's attention and gain the trust of both a wider public and other service providers.

“I think they [the public] feel more confident if the individuals are professionals and that's just the way society is, and I think it depends on the character type of the person phoning, some people need that authority figure” (Ashley).

Professionalism is associated with greater legitimacy of purpose, more credibility within the wider community, financial accountability, and a more organized hierarchal 'business-like' structure. While the ADAO feels that it needs to become a more professional organization many within and outside of the ADAO already felt that the ADAO is a professional organization. Board members described how in terms of financial accountability, and the ability to balance their books the ADAO is a professional organization. Board and staff members also described how conduct between ADAO members, and between staff and the public is also professional. In terms of public perception, many outside of the ADAO assume that the ADAO is a professional clinically run group staffed by experts because the ADAO has the appearance and the “trappings of an established larger professional organization”

(Beth). The ADAO is in the phone book, it has a toll free number, newsletters, booklets, website, charitable and corporate status, and the ADAO runs publicized activities such as bingos and golf tournaments. Additionally according to many health professionals the ADAO is both a professional and credible organization:

“I just can’t believe how that group has developed into such an astoundingly significant organization in town, I mean it is just remarkable what has been done by that group, I get goose bumps actually” (Kelly).

This interviewee attributes the ADAO’s success to the hard work, comprehensiveness and drive of members of the ADAO, however she does focus on the influence those clinicians and other service providers have had on the ADAO’s organizational growth:

“People like Dr. Dave Erickson were very instrumental in fostering the development and fostering the recognition and acceptance of this being a very credible organization, we (CMHA) still do a lot of mail outs if we can for the group to promote the credibility as well of the group, because I think we have a fairly good reputation as well in town” (Kelly).

In this way it is through its association with, and recognition by, other professional service providers that the ADAO is seen to be professional. The ADAO’s position within the city is seen to be both a product of its own skill and enthusiasm and its networking with ‘professional’ practitioners and services within the city. This helps to contribute to the organizations ‘anxiety’ about its professional status. For the members of the ADAO the creation of a space in which the ADAO is recognized as professional for its own independent achievements is instrumental for its growth as a service provider.

6.4.3 Including professionals

The ADAO has tried to become more ‘professional’ in its appearance and in practice in a number of ways. First, the ADAO has included more ‘professionals’ who have clinical training and post secondary education as staff and on the board of directors.

“We started hiring only people with higher education...people didn’t have to have anxiety anymore but they had to have a master’s degree pretty much to get in our door” (Beth). Additionally including more professionals to the mixture of knowledges at the

ADAO enhances the range and diversity of approaches to anxiety conditions that is central to the holistic mandate of the organization:

“We want, we need more professionals, we need to bring in advisors, because we need that, you need the sort of getting help from all available aspects, not only physicians, it could be a psychologists, it could be a talking to a counselor, to someone who has had the disorder and it could be a homeopathic approach, and ours is an organization that welcomes all of these methods, whatever works for the individual, you don’t only go one route”(Ashley).

6.4.3.1 Places of professionalism

Second, the ADAO moved its office from the executive director’s home to a separate building that houses non-profit organizations. The site of the ADAO was a point of controversy for various members of the ADAO. For some, the original office, located in the executive director’s apartment was a “refreshing change from board rooms”, “separate from a cold business formality”(Hannah). Thus the office was more informal, comfortable, intimate, enhancing a sense that the ADAO is a “grounded organization”(Emma). Board and staff members “felt at home” in the space and were thus more inclined to ask questions, give input and participate (Emily). For others the ADAO’s original office was inconvenient, uncomfortable, without a proper board table. The space was also perceived as “unprofessional” for holding large meetings or greeting the public, which meant that the ADAO could not have a public space or face (Michelle).

When funds were available, the ADAO moved its headquarters to the Bronson Centre; a building that provided reduced rent for non-profit groups. As one interviewee stated the move “looked good on the business cards and books”, but for those who worked in the space, its characteristics were highly problematic (Olivia). The rooms were still small, and the office area: “too small to effectively work in, because it’s always getting cluttered”(Samantha). The echo and noise pollution in the room made the space seem “cold and uninviting”(Sarah). Ultimately the ADAO could not afford to keep the new office and the ADAO moved back to its original headquarters. The move back, for many interviewees, did not detract from its professionalism because the space, “very pleasant, very warm, is at the same time very professional and organized”(Madison). In

this way interviewees discussed how it is not the physical space that matters for a professional organization, but how that space is created into a place, and its sense of place:

“Having it at Cheryl’s place doesn’t have to be a problem, I mean you can still be very professional no matter where you are...it can give the sense of an unfair advantage because it’s not neutral ground. But it doesn’t have to. For myself, I have no problem being who I am wherever I am at this point. That’s because I’m bold. For some, it may be intimidating. Because you’re comfortable, you’re sitting on a chesterfield. It’s different from sitting around an office sitting on uncomfortable chairs. It can be...the tendency is toward a non-business focus, but the meetings are organized and run well most times” (Emily).

6.4.3.2 Labeling the organization

Third, the ADAO changed its name from the agoraphobia and peer volunteer association to the anxiety disorders association of Ontario in order to appear to be a more professional clinical organization. The current name suggests that organization operates within a wider geographic range and uses the clinical nomenclature of anxiety “disorders” to imply that the organization is connected to the wider professional health care community.

“The APVA didn’t give us clout in the community nobody wanted to hear that the clinicians or the community, they wanted to hear the big words, so we decided that when we got charitable status that it would be time to change the name... the ADAO works for us it gives us a lot more attention, it’s a lot more prestigious within the community. I think that while the medical terminology is the number one influence it has to stay this way, but I can guarantee you as we grow we will change it” (Cheryl).

6.4.3.3 Clinical language practices

Fourth, the use of clinical terminology and language has increased in members’ vocabulary and within ADAO writings. Through the use of clinical language practices the ADAO are implicating themselves in processes of professional authority and maintaining power:

“There is power implicit in using language of pathology...I see a person in all their various richness as a person, not as a label of science through the language

of pathology... but sometimes I think, this is an “anxiety disorder” and that can be a short cut way of helping them [ADAO and individuals] identify some of the struggles that individuals have and connecting to the wider medical culture” (Jessica).

According to clinicians interviewed it is important that the ADAO adopt forms of expert power/knowledge and maintain its use of clinical terminology. This is because clinical language is associated with effective communication and identification in health service provision:

“Professionally within the mental health social services field you have got to have terminology to be able to talk to a person, and to explain to them you are not able to do what you want to do, having identifiable labels is a factor for getting them to see the psychiatrists” (Kelly).

Over the years of interviewing ADAO members (since 1997) it has become apparent that clinical terms and language have become more naturalized and unproblematised in talking about anxiety, panic and agoraphobia. Clinical terms are evident in the newsletters, anxiety workbook and in the development of a children and youth education program that is explicitly cognitive behavioral. The process of clinical labeling and use of cognitive behavioral (CBT) language is a sign of the eroding boundaries of the ADAO, due to its networking and partnerships with clinical service providers. It is also an example of the ADAO's desire to privilege expert professional and academic practices. By using CBT the ADAO has further informed some of their initial approaches to anxiety conditions. Yet additionally, in using psychological discourses, such as cognitive behavioral therapy, the ADAO is making a gesture of concession to a clinical audience. It is a kind of exchange in which the ADAO agrees to use and accept clinical understandings in order to secure for itself a safer place in which it can continue to develop and express its own unique ideas.

However, the ADAO does not adopt all dominant clinical discourses in the same manner. Biomedical or pharmaceutical treatments are approached with much more caution, and at times contested creating divisions between communities within the city.

“Well I know that we had problems with the Royal Ottawa, we invited them, we invited one of the great researchers over there to be a masters of ceremony, speaker, the honoured guest. He declined, because we don't represent what he

wants basically, we don't think. We need the pill and that's what he is studying, how to create more pills what pills do you need he was working on some part of the brain" (Beth).

The lack of receptiveness to biomedical approaches is a reflection of the kinds of networks the ADAO has developed, the personal experiences of those at the ADAO, and the responsiveness of various organizations and institutions to the ADAO's interest in collaboration. Not fully adopting biomedicine is an example of resistance to (and resentment of) various forms of knowledge and power.

6.5 Reclaiming the capacity for (self) authorization

6.5.1 Introduction

In Foucault's description of governmentality clinical power structures and expert knowledges of the clinic are normative and dominant while non-expert discourses are largely subsumed or resisted. But processes of governmentality also provide examples of how clinical discourses and forms of power/knowledge are incorporated and resisted in complex and sometimes contradictory ways. In this way I argue that the ADAO is not forcibly dependent on expert knowledge; there are resistances and differences to expert/clinical knowledges in forms that can often be quite subtle (Kangas, 2002:303). The ADAO is not a passive recipient of expert knowledge, nor is the process by which the ADAO has taken on expert knowledge a simple, easy or straightforward one. It has at times been a very uncomfortable process that has been fraught with argument and complication.

For some, within and outside of the ADAO, adopting expert discourse is a sign of growth and is well received, resulting in increased clientele and networks of other 'professional experts. For others, within and outside of the ADAO, capitulating to expertise has been an invasion of territory. The adoption of expert knowledges has resulted in a variety of criticisms amongst differently positioned interviewees. First, the ADAO is making claims to areas to which it does not belong and knowledges that it does not have. Second, clinical experts are taking over spaces within the ADAO that should be more clearly defined in opposition to professional clinical practices, as an alternative space of healing. Third, letting go of earlier holistic ideas in favor of more

clinical opinions and approaches to anxiety conditions does not guarantee recognition by dominant clinical service providers and experts because according to many clinical care service providers: “no matter what ‘knowledges’ are adopted the ADAO will always be characterized as a ‘self-help’ and thus lesser form of service” (Jacques).

There is considerable resistance amongst those interviewed within the ADAO to its incorporation within the clinic. Many interviewees were fearful that this would “dilute the community” (Alexis), that it signals the end for the organization, that it goes against some of the original and motivating visions of the organization, and that many of the voices and stories within the organization would be silenced.

“Well I hope it doesn’t, um, become and us and them um, but at the same time, I think the ADAO should protect itself so that it doesn’t lose its own authority to do its business the way it wants to do it. If it wants to include aspects in its therapeutic approach that the medical professional thinks is right...but, I don’t think it, it should put itself in a position where it’s not allowed to be experimental” (Chris).

In this section I provide examples of how the ADAO resists or modifies forms of clinical knowledge in order to foster spaces where difference is possible rather than replicating spaces and services that already exist.

6.5.2 Transforming clinical language

While the adoption of CBT is an example of the ADAO’s desire to privilege expert professional and academic practices, the ADAO has developed CBT protocol in ways that are different from psychological practices, for example placing an emphasis on nutrition which is not included in most clinical writings, and by resisting the use of certain labels. Clinical language is seen to be part of a patient-clinician hierarchy that helps to perpetuate unequal power relations in which the clinician is seen to be the one in the powerful position. These language practices involve processes of identification and labeling which are often stigmatizing. Thus within the ADAO it is important to “not be locked into a label mentality” (Chris) and actively use language to disrupt conventions of mental health writings.

“ADAO has chosen to use inclusive, supportive and meaningful language when referring to what are usually called anxiety disorders. Therefore throughout our booklet (workbook) we use the words “condition” and “persistent” to replace the current recognized medical terminology “Disorder”. Because “With labels such as “Disorder” we separate ourselves from the people who need us most and whom we also need. We unconsciously create barriers to real support, add to personal embarrassment and shame, and foster discrimination and isolation... in time our associations name will change to reflect this commitment” (ADAO Educational Guide, 2001a:1).

According to interviewees it is also important for the ADAO to contest clinical language because it is an expression of the rigidity of clinical power structures, rather than flexibility or diversity of thought:

“Doctors suggest or prescribe medication, the ADAO does not necessarily preach that, each individual has their own choice, so therefore they provide options and alternative methods and they let the individual choose, a doctor might not necessarily provide the alternatives, so that is there way of practicing, but in our society doctors are brought up prescribe something rather than offer an alternative because they might not necessarily be aware of the alternatives or it contradicts their way of being educated themselves” (Amy).

6.5.3 Challenging professionalism

While in section four I noted that some interviewees’ discussions of ‘professionalism’ challenge traditional definitions of the professional associated with business and clinical practices and structures. For those interviewees what makes an organization professional involves a different, yet connected, set of criteria such as: a diffuse or lack of hierarchy, characterized by a lack of a traditional paternalism; the centrality of care and support structures; the ability to network; openness to ideas and willingness to share knowledges; and the ability to carry through with projects and provide accessible and useful services. What many interviewees saw as most professional about the ADAO was its commitment to its membership and inclusiveness of a diverse range of ideas and individuals.

“The ADAO is not like a lot of other groups or organizations and health institutions...I think the people in the ADAO are very much focused on trying to help people, its not the least bit bureaucratic, every one is approachable in the organization and I think that is very uncommon, that makes a big difference, in terms of making it feel like a community to, you know, there is just no bull, it’s just I don’t know how to describe it but like for instance in other health

organizations there is always people around that don't focus on the people they are trying to service" (Hannah).

6.5.4 Reframing expertise

The most prevalent expression of resistance to the pressure to becoming more clinical was a rejection of the association between clinician and expert/professional. Interviewees discussed how the meaning of expertise needs to be reframed in terms of the first hand expertise and knowledge of anxiety conditions. Thus marginalized forms of care need to be thought as a kind of expertise and knowledge, which is central to organizational development (Gleeson and Kearns, 2001, Wilson, 2002). In this way sufferers are involved in a process of reclaiming authority over their own experiences in an attempt to challenge or resist forms of clinical expertise or to share in that authority (Hawkins, 1993; Frank, 1995; Couser, 1997). By transforming the identification of expertise with people who are not situated in positions of authority, interviewees increase the authority they have over their own lives. Through a recognition of the importance of sufferers' experiences the ADAO does not fully accept a dominant version of expert as detached professional and has reframed expertise in terms of people who have first hand knowledges of anxiety conditions, and people who can empathize and care for others. Redefining who has 'knowledge' and who is the expert is a result of rethinking whose experiences should be counted and listened to, as well as a revaluing of care. In this way forms of care become a type of expertise and valued knowledge.

The discussion of lay expertise is connected to the question of whether or not volunteers, staff, and board members need to have experienced some form of anxiety condition. It is also connected to the fourteen-week program where the issue of who can provide 'therapy' and the efficacy of clinical knowledges such as CBT in the hands of a trained professional in comparison to a 'lay' program instructor has been debated. Many clinicians outside of the ADAO have rejected the ADAO's fourteen-week program as ineffective because for them without professional guidance CBT programs are not as effectively managed. One interviewee who works for the ROH's Anxiety Disorder unit outlines many of the key themes expressed by those outside of the ADAO:

"I think it's fantastic to have that kind of a program [Fourteen-week program]. I think it would be important that when they have people in their program, they

were able to identify folks who needed a different kind of expertise. So for example, you can have panic disorder, and you can go out and buy yourself the anxiety and phobia workbook...and you can read all the stuff, and you can implement it, and you can do your own exposure, and there are going to be some folks who can do that. There's another group of folks who really need to be in touch with like-minded people, and that's more the AA style community support. Where they can get education, they can talk about their struggle...And I don't see that as less than the kind of treatment we offer here. I see it as different. The issue becomes when does using cognitive behavioral therapy principles become treatment that should be based in a health care facility or where the group leaders are health care providers. The jury is out on that one...because there are some folks in the medical community who would be concerned that a self-help group is treading into a treatment area. When you start to do cognitive behavior therapy, um, it's like any other sort of, um, psychiatric tool. You can use CBT principles in your day to day life, and all the self help books are full of it, but CBT in the hands of a skilled practitioner, the tool will be used in a different way. It's like listening, you can talk to a friend about something, or you can talk to somebody who's an interpersonal psychology person. The intensity and the, willingness to take risks and the skill to be able to dig yourself out of a hole are maybe different" (Stephanie).

Within the ADAO program instructors without clinical backgrounds identify their first hand knowledge of anxiety disorders as central to their expertise and as what is important in instructing the course. Program instructors with clinical backgrounds feel that while first hand experience is useful, good training and a technical understanding of anxiety disorders is just as important if not more important. Though most interviewees who had some experience of panic felt that the ADAO should have volunteers, workshop facilitators and board members who are sufferers themselves, some highlighted that what was really important was to be understanding and empathetic. In this way the 'layness' of knowledge is connected more to the quality of care than similarity or particularity of experience. This echoes what Joan Tronto describes as a care ethic, where care is not associated with particular persons but where care is a practice that is reliant upon a political commitment to value care and practices of care, especially forms of care that have been historically devalued i.e. lay expertise (Tronto, 1993; 1996). A care ethic is grounded within a politics of difference and the importance of interdependence. Thus in accepting difference one's own sense of self is viewed as positive rather than as a threat to social stability (Mackay, 2001:153).

6.6 Conclusion

This chapter focused on a number of issues. First, the chapter explored how processes of governing the self are implicated within the history of mental health. Second, the chapter examined the effects that the stigmatization of 'mental disorders' has had on persons with anxiety conditions, notably panic and agoraphobia. Third, I discussed how the ADAO is structured in relation to expert knowledge and how it has consciously and unconsciously adopted, and sometimes resisted, professional clinical discourses into its organizational structure, language practices and mandate. The ADAO is an example of how governmentality, care/practices of the self and the ethical self are malleable processes involving both capitulation and resistance.

As mentioned in chapter four, one of the aims of the ADAO is to demystify the stereotypes and misperceptions about anxiety disorders perpetuated through the stigma of mental illness. The ADAO feels it can best disseminate its information and create awareness campaigns if it is seen to be an organization that is professional. However, the ADAO's focus on being professional involves adopting forms of governmentality, i.e. expert clinical knowledges, that result in devaluing of forms of care that privilege non-expert experiences and knowledges that have historically been central in defining the ADAO's 'community'. This also results in replicating the model of the healthy citizen as causes, processes and symptoms of mental illness are given meaning by clinical practices in ways that reinforce the division between what is and is not normal, and thus reinforce the separation between the disordered sufferer and normal productive person.

Clinical expertise and knowledge dissemination is focused on getting the person back to a state of active and productive 'normalcy'. While this is centrally important for persons with anxiety conditions, the process of bringing the sufferer into a state of normalcy is more concerned with outcomes and end products rather than daily-lived experiences of between being healthy or ill. Thus the message is you can get better, you can live a normal life again, and where what is normal is an absence of panic or anxiety. This message does not allow for those who do not get better, nor for an account of the time in-between being well and unwell. Nor does it recognize anxiety conditions as part of a continuum, as discussed in chapter two, that affect those who are 'healthy' and 'unhealthy'. The message is not, these are the conditions and barriers experienced by those with panic, how can these dilemmas and problems be directly addressed? Clinical expert knowledge directs us on how to be well where becoming healthy involves a process of following and adopting experts.

In this way this chapter discusses another central issue pertinent to the creation of the clinic, self care ethic and normative concepts of the healthy citizen- the function of expert knowledge, professional discourses and the reliance on that expertise. The metaphor of 'mind' in relation to this issue addresses dilemmas generated by the meanings, stigma and 'object' (Foucault, 1967) of 'mental' illness through the knowledge production of the clinic, and discourses within the ADAO. In this chapter I have further explored processes of governmentality and the power exercised by expert knowledges that help to shape and delimit our identities, subjectivities and communities. Governmentality is connected to the normalization of experience and the creation of categories of deviance and disorder linked to the stigma of the mental, of being "all in the mind" (Davidson, 2002).

The chapter is reflective of an ongoing tension within the organization and amongst interviewees, discussed throughout the thesis, about the balance between networking with other, larger and more dominant clinical organizations, and maintaining its own vision. This tension or balance is about the potential for creating alternatives spaces, or spaces of difference, that do not duplicate but supplement or allow for different voices and knowledges from those spaces created within institutions, clinical practices or the formal third sector, what I have described as part of the process of health citizenship. By drawing on state-like qualities of the more dominant clinical institutions populated by experts and professionals the ADAO can better accommodate the demand for services that accompany increased needs. But, by drawing on grassroots origins, volunteer organizations like the ADAO can better identify with the needs that those institutions within the clinic and state failed to identify, or had not even considered (Brown, 1997:117). For some, the ADAO's incorporation of clinical knowledges is a sign of being taken over and subjugated by dominant power structures. But, by adopting those dominant clinical discourses the ADAO is able to network with more organizations and the potential for knowledge sharing amongst those organizations, through the creation of spaces and relationship of trust and friendship, is advanced. This process of sharing knowledges, explored in a different way in chapter three, has transformative potential for both the ADAO as well as expert organizations themselves: both become more receptive to the possibilities of the other. Therein lies a central tension for the organization.

The following two chapters do not address this tension directly rather they restructure the question of creating spaces in which knowledge sharing is central. Chapters seven, 'heart', and eight, 'breath', move away from discourses within 'the clinic', discourses central to this chapter and the previous chapter 'body' towards discourses that are structured in relation, in opposition, or as a form of resistance to those discourses. In so doing the possibility of fostering health citizenship is enhanced. The following chapters focus more on the possibilities of subverting and transforming the bodies and expert knowledges that sustain certain clinical discourses and practices. In this way chapters seven 'heart' and eight 'breath' explore in more detail how the ADAO has created a space for itself conducive to sharing knowledges, its own sense of place, identity and community within the broader local and national context.

Chapter Seven - Heart: Connecting the self

“Our unique character comes from our commitment to showing compassion and concern for individuals who have been ignored at the biopsychosocial realm. At present in Canada and in Ottawa specifically, there is a lot of focus given to treating the anxiety disease, but not the illness. Researchers have spent a lot of time and money trying to figure out what causes panic disorder, obsessive compulsive disorder, generalized anxiety disorder etc. are and as a result have developed numerous medications and therapies to support treating the disease. Unfortunately very little focus has been paid to the individual him/herself who has to go home each night after therapy and suffer, perhaps alone or with frustrated family and friends who are at the ends of their own ropes. We were established to provide the additional support the individual needs to treat their illness... the way the disease assists in the manifestation of physical, spiritual, mental and emotional needs becomes the illness... for so long, people with agoraphobia and panic have been left without the additional support to treat their illness. Where are they to turn when nobody understands their conditions? By providing continual encouragement and helping to motivate the individual with panic and agoraphobia we are helping them raise their spirits, work with their emotions, think more clearly and become active again” (APVA, 1998a:36-37).

7.1 Introduction

The previous two chapters, ‘body’ and ‘mind’, focused on ways in which models of the healthy citizen are incorporated and adapted by the ADAO and its membership. This chapter builds on those chapters differently, focusing more on the development of health citizenship rather than the healthy citizen. But similar to the previous chapters draws upon embodied metaphors as a point of departure. Like the words body and mind, ‘heart’ carries powerful connotations about self and identity (Birke 1998: 197). The heart is a metaphor for the self as characterized by attachments to others. ‘Heart’ highlights how identities and communities are formed within the context of geographies and relationships shaped by a complex set of intersecting social, political and economic determinants. The metaphor of ‘heart’ is connected to characteristics of the ADAO that interviewees discussed in the context of what makes the ADAO distinct and different from other service providers within Ottawa. These qualities include: an ethic of care; empathy; trust structured through informal relationships such as friendship; openness and receptiveness to a wide variety of ideas and perspectives; and the fostering of relational autonomy. These characteristics involve an understanding of the world as relational and of human relationships as interconnected and intersubjective. They focus on how connection to others is a positive attribute rather than a liability of dependency.

All of these characteristics are important within a model of health citizenship, as organizations with these attributes are more focused on the importance of lay knowledge, which is necessary to foster health citizenship. These characteristics suggest the unique and important contribution the ADAO, as a sufferer led initiative, can make as a mental health service provider. Within literatures on self-help, community, grassroots and volunteer based organizations the characteristics of care, empathy, friendship and openness are well discussed. However, there is little discussion within this literature, or within geographical writings, of the importance of relational autonomy. Thus, this chapter focuses on relational autonomy as a quality of the ADAO.

Through an analysis of relational autonomy this chapter explores how the ADAO claims a space for itself that is mindful of and negotiated through wider relationships and practices of power/knowledge. What is the balance for an effective community, between having its own sense of self, and a self that is connected to others? These questions are connected to autonomy because “autonomy involves choosing and living according to standards and values that are in some plausible sense one’s ‘own’” (Friedman, 2000:37). This chapter explores the ways in which the ADAO has created and negotiated a place for itself within the wider context of health care in Ottawa. The chapter examines how the ADAO has created for itself an autonomous space, its own space, defined by its capacity for relational autonomy - a space in which one gains a sense of autonomy because of supportive, caring, social relationships and a sense of ‘community’. It is within this space that the importance of interdependence, encouraging self-trust and self-reflection is emphasized. It is a space that fosters what Diana Meyers calls ‘autonomy competency’- “the repertory of coordinated skills that makes self discovery, self definition, and self direction possible”(Meyers, 1989:76).

The focus on relational approaches to autonomy helps us analyze the implications of the intersubjective and social dimensions of selfhood, identity and community for conceptions of autonomy, moral and political agency (Mackenzie and Stoljar, 2000:4). Developing relational autonomy competency is central to the ADAO. This involves skills that do not encourage the creation of individualistic atomistic individuals, but individuals who recognize that autonomy is contingent on embeddedness and connection to others. It is through the positive reframing of dependency relations that the ADAO plays a central role in the fostering of autonomy competency. In this way the ADAO also distinguishes itself from other service providers and creates its own supportive space where sufferers

can exchange their feelings and lived experiences. This creates a place in which people do not feel abnormal, alienated and isolated; conducive to the expression of ideas of self-exploration, self-definition and self-trust.

This chapter is subdivided into four main sections. Section 7.2 helps to explain what autonomy competency and relational autonomy competency is. Section 7.3 expands on section 7.2 by illustrating how autonomy is contingent on positionality and context. Section 7.4 explores the ways in which relational autonomy competency is fostered by the ADAO. And section 7.5 describes the ways in which the ADAO helps to create organizational autonomy. Section 7.4 and 7.5 more specifically shows how the ADAO's capacity for fostering autonomy through sociability acts as a model for anxiety sufferers and other service providers. This section is concerned with how relational autonomy competency within the ADAO helps to create spaces in which difference is possible rather than suppressed. However, section five also highlights how the ADAO's 'expansion' and collaboration with other service providers may compromise the ADAO sense of autonomy competency or effective relational autonomy.

7.2 Relational autonomy

7.2.1 Introduction

This chapter builds on the literature review of autonomy in chapter two, with a more sharpened focus on the topic of relational autonomy and the work of Diana Tiejens Meyers (1989; 1997; 2000). The issue of autonomy is connected to the normative ideals of the Cartesian mind/body dualisms discussed in chapters 'body' and 'mind'. The normative autonomous self has historically been envisaged as a process by which 'man' [sic] who is essentially alone, suddenly springs out of the earth and is suddenly fully mature and autonomous- like mushrooms (Hobbes in Benhabib, 1992). This image of the autonomous subject is highly contested as it neglects the effects and importance of child rearing in the development of personhood, or that there are large periods of dependency through which we develop capacities like autonomy (Okin, 1989). From this image of the Cartesian 'mushroom' subject autonomy derives its spatial form at a variety of spatial scales- the sharply bordered self that is extended into the form of the sovereign state (Elshtain, 1994). Autonomy is bound up in the construction of both spatial metaphors and in the spatial imagining of the individual. The Cartesian self and body, is a subject defined by its autonomy- an impermeable body controlled and mastered by a rational,

autonomous mind. Thus the experience of panic or anxiety, along with other 'mind disorders' has historically precluded the possibility of an autonomous self.

Autonomy is a central issue for persons with anxiety conditions such as panic and agoraphobia for a number of reasons. First, people with agoraphobic avoidance behaviors, including those interviewed, often describe how their spatial immobility impedes their sense of spatial autonomy, to move to and from various geographies as they desire or need. Second, as I have argued in chapters 'body' and 'mind', panic and agoraphobia contributes to lack of self-trust and confusion about self-definition that are fundamental for developing autonomy. Panic and agoraphobia make people less confident about exercising their autonomy in certain areas of their life; because they are unsure if they can be autonomous, thus shield themselves in relationships and spaces of dependence that can be debilitating.

Marilyn Friedman describes this as "autonomophobia", or fear of autonomy, which is connected to the experience of agoraphobia and panic (Friedman, 2000:45). Friedman focuses on the fear of the autonomy of others. In the case of agoraphobia and panic autonomophobia is more closely associated with a fear of being able to control one's self independently and thus act autonomously. Agoraphobia and panic is a good example of how people develop unhealthy dependencies on spaces and places, creating zones of safety that are both enabling and disabling, because they are fearful of what will happen to them in those various spaces, or are thus fearful that they cannot do anything in those spaces, they cannot act competently or autonomously. Here dependency on a particular space as 'safe' is problematic. Attachments to the space and to those within the space are governed by fear and, thus, are limiting. This form of dependency should be differentiated from other dependency relations, which are viewed positively in processes of relational autonomy.

The proceeding sections of this chapter explore how relational autonomy and the connection between the self and the social is central to the ADAO's programs, mandate and aspirations. This chapter does not suggest that other service providers do not foster relational autonomy, but that relational autonomy is a particular quality of the ADAO that is important for the ADAO's mandate and that allows the organization stand out within a network of anxiety service providers. I am particularly interested in Diana Meyer's discussion of autonomy competency and the ways in which the ADAO fosters relational

autonomy competency within the organization. The ADAO creates a space in which the primary skills of autonomy competency - self-definition, self-direction, and self-knowledge - are negotiated (Meyers, 1989). They do so in a way that focuses on the interconnectedness of individuals and sociability, thus the ADAO is engaged in a process of relational autonomy competency. I am not interested in autonomy competency as a checklist where people must follow a set of criteria in order to be autonomous. I am interested in exploring the belief that autonomy is a situated process that is both transformative and contributes to an intersectional identity. An intersectional identity entails analyzing the social significance of one's community of origin, disclosing to oneself the ways in which associated norms have become embedded in one's own cognitive and motivational structure, appreciating how entrenched they are, and assuming responsibility for the ways that one may repeat them (Meyers, 2000:159). This contributes to autonomy by connecting individuals to systemic social relations and to the social meanings of those structures (Mackenzie and Stoljar, 2000). An intersectional identity is similar to Lorraine Code's description of the ecological perspective of the self, which is based on relational autonomy (Code, 1995; 2000). The image of the ecological is meant to remind us of how subjects are organic, intersubjective and social beings, rather than understanding the subject and thus autonomy as individualistic (Code, 2000:197). It is a perspective in which mastery over one's self, over others, or one's environment, the goals of an enlightenment legacy and normative subjectivity, are viewed as problematic. An ecological perspective of the self resists the desire for a contained, homogenous unified self in favor of reconfiguration, difference and pluralism. Ecological thinking, and relational autonomy, disrupts the social imaginary governed by the rhetoric of autonomous individualism (Code, 2000:202). Both perspectives decenter the place of the individual relative to his/her context and situate the subject within a series of interconnected communities. Thus both relational autonomy and an ecological perspective highlight the importance of intersectional, relational selves in the creation of community.

7.2.2 What is relational autonomy competency?

The term relational autonomy arises from feminist criticism of traditional ideals and notions of autonomy as individualistic and rationalistic. Diana Meyer's concept of autonomy competency is motivated by a concern to explain the autonomy impairing effects of oppressive socialization for women and to develop a theory that is able to

explain how agents who are subject to oppressive social circumstances may nevertheless be partially autonomous, or autonomous in certain aspects of their lives but not in others (Meyers, 1989). For Meyers' autonomy is a matter of degree - it is episodic, resulting from individual events; and programmatic, affecting entire areas of one's life (Meyers, 1989). Autonomy competency is achieved through the development of a variety of skills that contribute to self-definition, self-direction and self-knowledge. These skills should be viewed as qualities and goals present, at different times and in different spaces, within the ADAO and its programs. They include (Meyers, 2000:166):

- 1) Introspective skills that sensitize individuals to their own feelings and desires, which enable them to interpret their subjective experience.
- 2) Imaginative skills that enable individuals to envisage a range of self-concepts that they may adopt.
- 3) Memory skills that enable individuals to recall relevant experiences not only from their own lives but also experiences that their associates have recounted or that they have encountered in other forms.
- 4) Communication skills that enable individuals to get the benefit of others perceptions, background knowledges, insight, and support.
- 5) Analytical and reasoning skills that enable individuals to compare different self-concepts and assess the relative merits of those alternatives.
- 6) Volitional skills that enable individuals to resist pressure from others to embrace a conventional self concept and that enable them to maintain their commitment to a "self portrait that they consider genuinely their own, that is authentic" (Meyers, 1989).
- 7) Interpersonal skills that enable individuals to join forces to challenge and change social norms.

In addition to the list of autonomy competency skills Meyer's describes, I add a skill not discussed within work on autonomy competency that I term spatial knowledge skills. Autonomy is connected to spatial relations, culturally specific and historically defined,

both within and outside of the body that affects our subjectivity and sense of identity. Spatial knowledge skills enable individuals to recognize the importance of space and place in relation to the construction of an autonomous self. Meyer's autonomy competency skills focus primarily on the self in relation to social environments or processes of subjectivity (social norms, values, beliefs), and the self in relation to other people and groups who influence a sense of selfhood - rather than the complex interrelationship between our physical environments, social environments and identity.

The centrality of spatial relations for autonomy competency is particularly evident in processes of disablement, impairment and disability. Often mobility/autonomy is discussed within disability studies in terms of accessibility or as being 'barrier free'. The belief here is that without socio-spatial restrictions one would be able to exercise and direct one's actions more autonomously. Within discussions of disablement, impairment and autonomy systematic structures of discrimination and a notion of 'ableism' are primary obstacles in developing autonomy. This was described by many of those I interviewed who were agoraphobic in terms of the forms of discrimination they felt within socio-political structures and in particular within the culture of their workplaces. Additionally, problems that family, friends, other clinicians or co-workers created for the individual affected their sense of autonomy and well-being.

Ultimately for Meyers the development of autonomy competency skills is a means towards understanding one's "authentic self" (Meyers, 1989:77). The concept of the authentic self is a highly contested issue, however it is central to Meyers discussion of relational autonomy competency. The authentic self should not be understood as a core that can transcend its context and processes of socialization, or that precedes, preexists and preempts any other factors or life experiences. The authentic self should also not be conflated with an 'original' self, if such a self exists. The authentic self characterizes who we are, and what we want but is not fixed or immutable, it is transformed over time and place. For Meyers the authentic self consists of "the repertory of skills that make up autonomy competency along with the collocation of attributes that emerge as a person successfully exercises autonomy competency" (Meyers, 1989:92). Thus the authentic self is never separate from the agent's environment.

For Meyers autonomy competency is relational in the sense that it can only be developed in the context of social relationships, practices and institutions. Social environments

foster the development of the self differently over the life course. Agents are more likely to develop those aspects of themselves that are socially reinforced and incorporate these aspects into their self-concepts. In this way the quest for individuality may be undermined by various conventions, roles and norms. Some environments encourage the growth of some skills at the expense of others. Western cultures for example encourage in women the skills of self-discovery because women are more closely associated with emotional receptivity and perceptiveness that are crucial for self discovery (Meyers, 2000).

However women are less likely to develop skills of self direction and self definition that men are more likely to be socialized to develop (Mackenzie and Stoljar, 2000).

Autonomy is a competency involving skills of self-discovery, self-direction and self-definition that involve reflection. Thus, Meyers sees self-realization as crucial to self-respect. (Mackenzie and Stoljar: 2000:17). In this way autonomy competency is more of a process in which self-understanding and self-definition is possible rather than a specific quality of an individual or group. The distinction between autonomy competency and relational autonomy competency is the extent to which sociability, interconnectedness and interdependence is central to self-discovery. Thus relational autonomy competency skills focus on how our choices are made in relation to, and affected by, other people.

7.3 Placing autonomy competency in context

7.3.1 Introduction- Procedural and substantive accounts

Autonomy competency as Meyers defines and discusses it is often described as an example of a procedural account of autonomy (Mackenzie and Stoljar, 2000). Mackenzie and Stoljar describe how within a procedural account of autonomy:

“[T]he content of the person’s desires, values, beliefs and emotional attitudes is irrelevant to the issue of whether the person is autonomous with respect to those aspects of the agent’s motivational structure and the actions that flow from them. What matters for [procedural] autonomy is whether the agent has subjected his/her motivations and actions to the appropriate kind of critical reflection” (Mackenzie and Stoljar, 2000:13-14).

For Meyers, as long as the subject comes to realize why they make the decisions they do and act on that realization in some way then they can be said to be autonomously competent. For Meyers’ autonomy is a process of reflection on one’s actions, no particular actions are more autonomy conferring than others. Individuals can choose oppressive ideals and goals and make oppressive choices that are still plausibly their own

decisions. What distinguishes autonomous people is that they have reconciled those beliefs that they incorporate into their system of thought (Meyers, 1989:30). While Meyers recognizes and discusses oppressive forms of socialization, what is most important is that individuals recognize that they are situated in contexts that shape their decisions and beliefs, even if they are oppressive. Exercises of autonomy competency can reinforce established reasons and courses of conduct, but it can also propel people into new directions (Meyers, 1989:96).

This section explores how autonomy competency skills and relational autonomy competency could be developed in the context of substantive accounts of autonomy. In contrast to procedural accounts of autonomy, substantive accounts of autonomy reject the content neutrality of procedural accounts and insist that autonomy can only be realized when one considers the specific contexts and preferences of agents (Benson, 2000). Substantive accounts reject the notion that autonomous choices can be made when socialization is oppressive. Within a substantive theory of autonomy oppressive socialization impedes the agent's ability to discern norms that are accepted and perpetuated by the oppressive context in which they are operating. Oppressive contexts are also linked to the impairment of one's sense of self-trust, self-worth and self-respect that undermines one's autonomy. Lacking self-worth is an obstacle that results in individuals making normative, and oppressive choices that are deceptively autonomous. Substantive accounts highlight how self-respect and self-trust are necessary conditions of autonomy.

Substantive accounts are about curtailing bad judgments we make that help to perpetuate an "illusion of choice" where there may be none (Foucault, 1996). To this extent, not only is relational autonomy competency about understanding why we believe or make the choices that we do, it is also about dispelling the myth that choice is always available, at any time, in any place and for anyone. Within substantive accounts of autonomy the creation of alternative and antagonistic choices rather than presumed informed consent is more central to the creation of autonomy. Additionally within a substantive account of autonomy there is a recognition of how the decisions we make not only affect our own sense of autonomy but the autonomy competency of others.

The context in which relational autonomy occurs is important for a substantive account of autonomy. Relational autonomy develops within a wide range of environments and

contexts, but develops differently in those various contexts, producing a different sense of subjectivity and identity. In this way the qualities identified by interviewees as central to the ADAO - care, empathy, friendship and its diversity of approaches - that help distinguish the ADAO from other service providers, also help to situate relational autonomy competency skills.

7.3.2 Coercion and autonomy

A good example of how context is central to the creation of relational autonomy, is a comparison between contexts that are perceived to be coercive in contrast to non coercive and how these varied contexts result in different autonomy competency skills and situate the way in which autonomy is developed differently. Interviewees, to distinguish the process by which they developed a sense of self and autonomy, often used comparison between the programs the ADAO offers and services offered by various clinicians; where clinical services were often described as coercive and the ADAO's programs as non-coercive. For example, many clinician-patient interactions are structured on the hope of developing relational autonomy competency in the patient. Within these interactions introspective skills and memory skills are central; imaginative skills and analytic and reasoning skills may be fostered depending on the range of options presented to the patient; while communication skills, volitional skills and interpersonal skills may not be well developed or fostered. Programs within the ADAO such as the fourteen-week program and support group that present a diversity of subject positions and highlight the efficacy and importance of alternative approaches are better suited to develop not only introspective and memory skills but imaginative skills, analytic and reasoning skills and volitional skills as well. And due to its group and participatory dynamic structured as a social setting with an informal flexible hierarchy communication skills and interpersonal skills may also be developed.

Criticism of the clinical system is that it often neglects the voices of those who are sufferers. That it replaces that voice with a more authoritative, more enlightened 'other' voice that is meant to create a better new self that is harmonious with the suffers initial agenda as opposed to something which is imposed or taken on (Frank, 1995; Couser, 1997; Nelson, 1999). Yet this 'other' voice is informed by different desires, needs and goals than those of sufferers themselves. While it is widely agreed that in clinical arenas patients should make autonomous decisions about their health care, certain degrees of

paternalism still remain reducing self trust and a person's ability to act autonomously (McLeod and Sherwin, 2000:266). People often subjugate their own beliefs and knowledge in favor of that of a clinician knowingly and unknowingly, thus the extent to which an autonomy competency is developed is an important question in the context of a patient-clinician relationship (Sherwin, 1998). Additionally, as Paul Benson argues, restricting a person's capacity for imagining through directing the subject using specific norms or directions can be viewed as a form of oppressive socialization (Benson, in Mackenzie, 2000:124). In this way, within a clinician-patient relationship is the process of therapy - often structured by authoritative forms and knowledges that the patient may not be familiar with, or fully understand - a process in which the patient can exercise autonomy? Many clinicians are aware of this and actively try to work against acting as an authoritative figure, towards a more equal distribution of power.

This is also not to say that coercion is not a problem within informal relationships. For example within ADAO programs group dynamics often involve aspects of coercion and pressure from instructors or other members in the group towards a particular perspective, practice or belief. In any group program, such as the fourteen-week anxiety management program, the personalities of the members help determine the way in which the program proceeds. However in a group structured by mutuality, in which equality of perspective and experience is stressed the foundation for autonomy competency is more likely to develop. Within the ADAO instructors of the fourteen-week program are made aware of the importance of creating and maintaining an atmosphere and group dynamic in which coercion from others, especially the instructors, is discouraged. This was extensively discussed amongst interviewees. As one of the instructors notes:

“People may initially come to get answers, to be given answers, that is not the process and that is made clear. And when they begin to realize that we can't give them the answers, that we are not the experts, the dynamic changes, people change their approaches to developing themselves, and to how they use the group and the program. The hope that some people have with clinicians is that they will cure them through various treatments and adherence to treatments, in the program following instructions is dispelled, as what becomes instructive are other people's experiences, other peoples support and other peoples encouragement and ideas” (Amanda).

In part because the ADAO has been criticized that it cannot claim to provide therapy, or provide an authoritative professional function, the ADAO defines itself as an educational organization whose function is to make the public and those with anxiety conditions

aware of a variety of opinions and approaches to those conditions. The ADAO ‘informs’, it does not provide answers, and those who approach the ADAO looking for answers are likely to be disappointed with the lack of any clear cut solution or promised cure. The ADAO is fearful of seeming to be authoritative and is conscious of creating an atmosphere in which coercion is actively recognized and worked against. The ADAO presents a wide range of options for sufferers that are both clinically oriented and non-traditional or ‘alternative’. The social environment in which the ADAO is structured is based on networks of support rather than being characterized as a place of treatment or expertise (which is not to say that people do not use or come to the ADAO and its programs expecting staff and instructors to be experts).

The different perceptions of coercion within clinical and ADAO settings does not mean that all participants of the ADAO develop a range of autonomy competency skills, or that patients of clinicians do not apply interpersonal and communication skills in other areas of their lives and spaces as a result of what they take from a clinician-patient encounter. However, interviewee’s descriptions, participant evaluations from the fourteen-week program, and newsletter articles suggest that many members of the ADAO develop a range of relational autonomy competency skills as a direct result of ADAO programs, while they did not as a patient. This is contingent on the qualities of care, empathy, trust fostered within informal social settings and the ADAO’s holistic approach to a wide range of perspectives on the etiology, treatment and management of anxiety conditions.

7.4 Exercising relational autonomy competency

7.4.1 Introduction

Relational autonomy is central to the purpose and mandate of the ADAO. Most community-based advocacy, educational and awareness groups have qualities that highlight the importance of relational autonomy. This is because the sharing of experience through social interaction, increasing public awareness and informing or demystifying beliefs are central to the process of changing social norms and changing people’s lives. Within this section I will provide direct examples of relational autonomy and relational autonomy competency using interviewees discussions and materials from the ADAO.

The ADAO helps to develop relational autonomy competency skills through its awareness and educational campaigns and programs such as the youth screen play, life potential program for young people, and parents guide to youth and anxiety and youth education program. The ADAO also develops these skills through its anxiety, panic and avoidance behavior management workshops, volunteer companion program, newsletters, publications and support groups where:

“Meeting with other people who have the same problem and sharing it with each other helped me to see that I was not alone and it helped me to find some kind of support and security. Thanks to this program today I feel so much better”
(Johanne, APVA, 1998b:4).

In this section I focus on three programs/services provided by the ADAO as examples of relational autonomy: the newsletters, the volunteer companion program and the fourteen-week program.

7.4.2 The newsletters

The newsletters published and distributed amongst members of the ADAO provide numerous examples of the importance of relational autonomy, and the centrality of fostering autonomy through sociability within the ADAO. The newsletters act as a space in which members can share their stories and learn, or take inspiration, from other people's stories and from information in the newsletters. The newsletters provide an example of the wide range of opinions and knowledges surrounding anxiety, and while there are distinct preferences towards approaches and beliefs about anxiety conditions, there is also a clear message that one person's preference is one option within a diverse range of beliefs and options. The newsletters create a space in which communication skills that allow members to learn about other members' experiences, knowledges and perceptions are developed. One of the aims of the newsletters is also to enhance volitional skills and act as a place in which members can feel free to talk about a variety of options, state their opinions, and make comments and suggestions about anxiety conditions. Ideally the newsletters aim to enhance interpersonal skills in order to build public awareness campaigns that promote social change and increase awareness about the daily-lived realities of anxiety conditions.

The importance of relational autonomy is clearly stated through a book review of Jean Vanier's "becoming human" whose central message is that "belonging is important for our growth to independence" (ADAO, 1999b:2). In this review we not only learn about how autonomy is not an individualistic isolated process, but a process that is situated and relational. The review points out the need to recognize the importance of the experiences of ill health in developing subjectivity, or health citizenship. As the executive director then remarks in the review:

"Jean Vanier understands that without trust and support from another person or persons, we may not find our independence. When we know we are connected we are then ready to become separate. This is a belief that the ADAO has carried throughout the development of its programming and we are so happy to see it somewhere that is so tangible and followed with so many other meaningful insights... the moment that we are recognized, or acknowledged by another human being, we are given an opportunity to see ourselves more clearly. Those who can show us that we are okay just as we are, are not telling us that we have to remain unwell, but while we feel as if we do, they will honor us anyway. They are telling us that we can be as wonderful and important to our community as all people are, even when we feel unwell. It is through our relationships with individuals who are living through all kinds of experiences that we will really find the essence of life and living" (ADAO, 1999b:2).

The newsletter serves an inspirational and informational function through a variety of different article types, where one article may fit into a variety of article types.

- 1) First, is the use of testimonial/didactic personal stories to aid in recruitment of membership and volunteers.
- 2) Second, are articles that focus on reframing the "other" that highlight progression of stranger to friend.
- 3) Third, are articles that develop both a sense of community and language based on common experiences.
- 4) Fourth, are articles about relationships and stories of support.
- 5) Fifth, are articles that could be described as progress or quest stories that often add an evaluative dimension to the links between the personal and the social.

6) Sixth, are “I” stories- stories about reframing the self where the construction of an autonomous self is actualized as a result of interaction and connection with others.

7) Seventh, are articles that use narrative to highlight the diversity of experience within the community. Often these narratives provide more detail about the experiences of panic and agoraphobia emphasizing the various ways in which people may experience these conditions.

8) Eighth, are treatment and management stories that offer suggestions on how to approach and manage panic and agoraphobia for both the sufferer themselves, and for others who may have to care for someone with panic and agoraphobia.

9) And, ninth are healing stories. From stories of individual healing through self-discovery, to healing through clinical care and alternative health practices (Rimke, 2000).

In this section I provide examples of “I” stories that directly refer to processes of relational autonomy. In one article entitled “the positive influence of others” the author describes how through the support and encouragement of others around her she has been able to accomplish goals and set new goals for herself thereby increasing her well being and sense of autonomy (APVA, 1997b: 2). In another article entitled “my first trip to the movies in fifteen years” the author, Nathalie, describes how her volunteer companion helped her go to the movies without having a panic attack (APVA, 1998a:6). For Nathalie going to the movies means being “one step closer to freedom” and one step closer to feeling autonomous. But she would not feel autonomous if not for the support and encouragement of her volunteer who was instrumental in helping her get through the experience of the movie and therefore for helping her help herself (APVA, 1998a:6). ‘I’ stories not only detail the experiences of participants, but how family and volunteers develop a better understanding of who they are and their sense of autonomy through the programs offered by the ADAO:

“I started panicking about twelve years ago. Throughout my bouts of panic I had a dear friend that I could always count on when things got rough for me.... I moved to Ottawa a year ago and started received a local paper called the Penny Saver... This is where I saw the ad for volunteers for the APVA. I immediately took action. I called up the director and signed up. I had been taken so well care of by the people who had supported me, that now I was feeling so well, I had to try and help another who was now experiencing the same as I. I met my first client in January... Even though I am the volunteer, she gives a lot back to me as well...

Volunteering is one of the most rewarding choices of my life. It is a pleasure for me to serve in this way and I hope that we will one day attain our visions for our association” (APVA, 1997a: 7).

7.4.3 The volunteer companion program

As described in the quote above, the volunteer companion program is an example of how relational autonomy competency is fostered within the ADAO. While one could never say with certainty that all participants feel they are more ‘autonomous’, or understand that autonomy is a relational process, anecdotal evidence from interviews and ADAO documents (there is an evaluation form for every volunteer companion match, as well as a bi-annual review of the match) suggest that various programs, including the volunteer companion program have resulted in increased mobility, associated with increased autonomy. This sense of autonomy was attributed to volunteer companion interaction and support. For example, the following excerpt illustrate how notions of autonomy, identified as independence, are predicated on relations of interdependence:

“Agoraphobia has shrunk my world to the size of a postage stamp and I have felt extremely depressed and isolated during acute agoraphobic episodes...with the kind and patient assistance of my volunteer, I was able to start going out again in a small way. I still panicked but I grew to trust the volunteer who reassured me that we could stop any activity if I felt uncomfortable doing it... My volunteer has opened the door that leads me back into the world. I now know that I will never have to be housebound again. The feeling of being trapped in one’s house is a nightmare and I am grateful to the agoraphobia and panic volunteer association for releasing me from that prison” (SM, APVA, 1997a: 3).

In this example above mobility is directly connected to a feeling of autonomy. Autonomy in addition to being about the ability to make a variety of choices that concerns one’s life is also about the ability to be physically mobile. Within a framework of relational autonomy, others are seen as both hindering and enabling accessibility and mobility. There was general consensus amongst interviewees that the fear and inability to go various places was a barrier to autonomous action and that the agoraphobic behaviors were not choices agoraphobics felt they had control over. In this sense overcoming agoraphobia was a central means by which autonomy could be achieved. Developing those skills of autonomy competency was contingent, for many interviewed, through the support and sociability they received from programs such as the volunteer companion program.

Within the volunteer companion program imaginative skills that enable individuals to envisage a range of self-concepts are central for effective goal setting while communication skills that enable individuals to get the benefit of the volunteer's perceptions and support are also important for an effective volunteer companion relationship, especially when setbacks arise. Primarily, the volunteer companion program focuses on spatial knowledge skills that are central to the development of autonomy. The ability to remap both public and private spaces as safe, and to understand the interconnected relationship between one's environment, one's bodily sensations and feelings is the ultimate goal of the volunteer companion program.

“[My client], her need for me was to have me there when she went to school. I would stay in the cafeteria, she would go to classes, and just knowing that I was there, she was able to function, to change the way she saw and interacted in class and not get anxious... Towards the end she was able to go to the university by herself, and I would arrive at a certain time later, I would be there for her at break, then I would leave early, and earlier, and now she is able to go to the university, and walk around and finish her classes. It is now an OK space for her and the anxiety around pressure in class is better, changed” (Amy).

7.4.4 The fourteen-week program

As discussed within section 7.3 of this chapter relational autonomy competency skills and autonomy competency skills are displayed within the anxiety, panic and avoidance behavior management fourteen-week program. In this program individuals are encouraged within a group setting to develop these skills in part through a sharing of experiences and difficulties with others in the group. Primarily, individuals who have experienced anxiety conditions instruct the fourteen-week program, but there are some instructors who have not experienced an anxiety condition. These instructors, who are mostly professional clinicians (social workers or therapists), are paired with an instructor who has had an anxiety condition. Instructors who were interviewed talked about their roles as facilitators and supporters. Most instructors felt that the development of autonomy was important for participants, but that autonomy needs to be structured and conceived of as relational, as part of learning from others:

“I feel as a facilitator it is important to foster a sense of independence, but also foster dependence within the group, so they are using the group, and not me... so we try to encourage if people use the group, the wisdom is within the group, within every single individual that is there, that they've got a goldmine at their disposal and they should be able to use that, don't just sit quietly and go home with it, try and use the group, and maybe that does create a sense of dependence,

but I don't think it is necessarily a wrong thing, it helps them understand and better themselves. It's about personal growth" (Brittany).

Another interviewee in the context of interdependence described a similar discussion about the roles of the group and facilitators:

"I think that when you are in any kind of collaboration around anything, lets talk about a group, or the fourteen-week program, there is also interdependence. People have different roles in terms of what the group is about. A facilitator and its members are interdependent, they are exchanging information ... I am saying interdependence, in order not to have this distinction between dependence and independence. I would not even talk about independence because I don't think there is such a thing in human relationships" (Jessica).

Previous to the fourteen-week program, the ADAO ran a twelve-week program taught by a psychologist affiliated with the ROH, Dr. Dave Erikson. But, due to group comments, increased funding and Dr. Erikson's departure from Ottawa, a new fourteen-week program that included more on nutrition and anger management was developed. One interviewee who went to the twelve-week program was critical of the way in which instructors or experts were positioned, both literally and metaphorically:

"The twelve-week course was taught by Dave Erikson, and he had two assistants... who sat outside of the circle of the table... and we knew what their names were, but that was it, it was sort of problematic and it made people feel really uncomfortable, us and them. I think that was really not well done" (Brittany).

What was noted amongst those who completed the fourteen-week program is that participants would not have embraced skills in the same way in an atmosphere structured along expert and non-expert divisions. Many of the participants within the fourteen-week program felt that volitional skills were much easier to embrace in a setting in which no one is perceived to be more knowledgeable than another, including the instructors.

Thus it is important that the fourteen-week group is meant to be a "collaborative, supportive kind of environment, it does not feel hierarchal, but I recognize it, I mean it is still a hierarchal structure" (Amanda). The instructors are there to "act as models", to inspire, inform and direct discussion and homework. The instructors are leaders, and as such, have more control over the group dynamic (Susan). The lack of a perceived hierarchal or authoritative structure within the group has to do with the way in which instructors situate themselves within the group and the direction that instructors provide for the group dynamic which is centered on the "supportive function" of the program:

“We don’t do therapy, it’s a learning type of group, we are just giving them information... it’s a skills group...and when people begin to realize that they change their approaches to developing themselves, and to how they use the group and the program. What becomes most useful and important are other people’s experiences, the support and inspiration they get from others in the group, as well as from us as instructors, support is the main thing they take away from the group” (Amanda).

The course revolves around the anxiety, panic and avoidance behavior management workbook, written and created by the ADAO. The anxiety, panic and avoidance behavior management workbook is meant to be used as a self help guide, in a group setting to promote greater social interaction, positive reinforcement and support, and within support groups (ADAO, 2002a:3). It can be used as a therapeutic tool when working one on one with a therapist, in order to develop workshops for agencies and businesses, as a support group resource, as part of an educational group, or for individual use (ADAO, 2002a:3-4). Comments made about the program and workbook suggest that the book was used in a variety of ways. As part of the program evaluations, participants indicated that the first six autonomy competency skills were developed, to different degrees, amongst participants. Participants described how these skills were acquired in relational and non-relational ways. Sometimes people gained these skills through homework activities by themselves, while at other times people gained these skills through sharing information, homework assignments and experiences with others within the group. Ideally however the workbook was designed for a group setting because:

“The group environment is essential in helping students to explore how they relate to their environment; it provides opportunities to learn about their development in a way that their processes can be modeled back to them. Groups are mini social structures that provide the opportunity to face attitudes, morals and values generally seen in the greater society. Finding comfort within that group through discourse and various activities will be a great foundation through which to begin one’s work through anxiety, panic and fear” (ADAO, 2002a:2).

Thus unlike individual homework, or individual work with a clinician:

“In the group there is a sense of community, a sense of group support. Listening to other people’s feelings of isolation, and that is beneficial, it gives them skills. It gives them hope and a lot of knowledge about themselves through the support of others” (Brittany).

It is this combination of support and sociability within the group environment that helps create relational autonomy competency skills:

“When people are participating in the group there is that ability to tap into a whole lot of other people’s experiences and the wisdom that they’ve gotten from those experiences. They have the ability to learn from other people in the group, and they also have the ability to teach other people, and that can be really gratifying and really self esteem building... people really learn a lot and it’s not just the material, it’s something that they learn about themselves, that may lead to other things like doing more for themselves, or doing the things they may have wanted to do but did not feel supported to do it”(Brittany).

The workbook reflects a diversity of perspectives on anxiety, alongside the increasing prevalence and importance of cognitive behavioral therapies (CBT) for the organization. The book is based on CBT practices and techniques common to CBT but also integrates deep breathing, nutrition, progressive muscle relaxation, and mindfulness techniques. Independence through support and empathy is a guideline for the fourteen-week program (ADAO, 2002a:9) As one instructor notes:

“We try to make sure that the goal is focused on being independent, through support and through listening...Listening helps us build trust, it helps them get better themselves, it works towards developing independence, but it also works at the same time towards developing trust within the group” (Emily).

In this way developing independence is connected to the building of networks of support and attachment. Relational autonomy is not only a process of constructing the self, but a means towards developing a sense of the group or community. Individual growth is connected to community development. Individuals can be empowered through relational autonomy competency, and those relationships can help forge bonds of individual and collective action. Thus, relational autonomy competency is a precursor for the effective development of community. Recognizing how we are connected to others and to the environments in which we are positioned helps to create change as well as social and political forms that empower individuals and groups.

7.5 The ADAO and organizational autonomy

7.5.1 The challenges of relational autonomy and organizational development

Relational autonomy within the context of organizations draws attention to several points. Autonomy and relational autonomy skills can be increased by the creation of a supportive environment in which these skills are practiced. Additionally, relational autonomy skills are also increased within an environment that is holistic, supportive of change, multiple perspectives and practices. Substantive accounts of relational autonomy involve

advocating for alternative visions and presenting a wider range of options for the public to select from. In the context of organizational development, relational autonomy brings to light the importance of how groups are formed and developed in different ways by people within and outside of the group. Any organization is never completely contained but requires other organizations and actors to develop its community and identity. For example the way in which the ADAO is constantly compared and framed in opposition to other clinical service providers by interviewees is an example of how organizations define their sense of self and demarcate their boundaries in relation to others. Relational autonomy on an organizational level implies networking, collaboration and expansion, but those connections may also help to erode the organization and its sense of feeling autonomous especially when situated within an oppressive hierarchy.

The availability of choice for the ADAO's membership, as well as the acceptance of multiple viewpoints, perspectives and treatments is described by Meyers as central for the development of autonomy competency skills. The ADAO's receptiveness to a variety of approaches to anxiety conditions have resulted in more collaborative partnerships within and outside of the organization. This diversification and networking for Barclay is a precondition of a communities ability to develop and sustain a capacity for autonomy, as autonomy is attributable to the ADAO's remaining embedded within a network of social relations (Barclay, 2000:57). A group's success as an autonomous agent is affected by its ability to share its ideas, its aspirations and its beliefs in conversation with others (Barclay, 2000:57). Many interviewees however are concerned about the extent to which decisions the ADAO have made are a result of oppressive socialization, that is not own of their own choosing, but choices that needed to be made in order to gain a wider network of allies, as well as more funding and prominence. Within a procedural account of relational autonomy the ADAO's decisions to make certain changes and directions, to adopt the visions of others and use it to transform its own self-concept and direction could be viewed as an account of autonomy competency. But in a substantive sense, one needs to ask if one is moving away from the central precepts of the ADAO. These visions are always subject to discovery and change, they transform over time. But transforming one's beliefs is not that same process as conforming to a set of beliefs that others desire.

Both individuals and communities need to consider which attachments should be celebrated, as well as, which shared values should be a part of the common good. This process both creates autonomy and requires autonomy (Barclay, 2000:68). Creating

autonomy through the fostering of ideas and spaces that belong to the individual and/or community, and requiring autonomy in order to have the freedom to express and develop those attachments and values. It is the freedom to express and develop particular values and beliefs that many interviewees felt was not as possible for the ADAO within Ottawa, and placed the ADAO at a disadvantage for being relationally autonomous. Interviewees' discussions of this issue are framed in terms of the boundaries and limits of autonomy for the ADAO, as well as, the meaning of autonomy, that is, the creation of a space that is plausibly one's own (Friedman, 2000).

Amongst many groups and organizations, autonomy refers to the ability to make one's own decisions without having to please those external to the organization. Autonomy is thought of in the context of bureaucracy as independent from funders, without having strings attached. Autonomy in this context is concerned with demarking the boundaries between what is inside and outside of the organization. But to suggest that organizations can exist outside of the networks and contexts in which they are situated, without being accountable, responsive or having to please those external to the organization is often not possible or realistic. Additionally failing or refusing to recognize that an organization, and organizational decisions are affected by internal and external forces is problematic and can result in organizations moving away from visions and desires that are central to their sense of growth. Knowing where ideas have come from is part of the process of being autonomously competent, of creating organizational self-realization and self-direction that results in further organizational growth.

But, to be relationally autonomous involves the simultaneous recognition and blurring of a constitutive outside and inside of the ADAO. Moving from Friedman's definition, an autonomous space for the ADAO, is not simply a space in which the ADAO can exercise its own desires and initiatives, but a space in which the subjugated knowledges and daily lived experiences of persons with anxiety conditions are recognized and acknowledged. Thus the ADAO's autonomous space is not conceived of as a private, contained space, but as a publicly available arena that further opens up the possibility of other spaces (physical, rhetorical, and agenda/ advocacy spaces), and new social imaginaries about what it means to have an anxiety condition and what it means to be human.

7.6 Conclusion

Coming back to the metaphor of ‘heart’ used in the chapter title, ‘heart’ is a metaphor for interdependence as both a positive attribute that contributes to the production of caring relationships, and as necessary for relational autonomy competency. The metaphor of ‘heart’ is connected to characteristics of the ADAO that interviewees discussed in the context of what makes the ADAO distinct and different from other service providers within Ottawa.

This chapter has focused on two interrelated issues connected to the construction of health citizenship. The first issue is concerned with how has the ADAO created its own sense of self within a landscape of service provision. The second issue is concerned with how relational autonomy is fostered within and by the ADAO. The chapter argues that the ADAO has an important contribution to make in terms of its focus on relational autonomy, within its context of care, responsiveness and diversity. These attributes make the ADAO a distinct and unique organization within Ottawa – creating a space the ADAO could call its own. Creating a place that is plausibly one’s own is a precursor to the development of alternatives to the normative model of the healthy citizen found in clinical service provision - spaces in which difference is possible and exercised and where alternative political forms can be created.

This chapter has also extended the discussion of what constitutes an effective balance for the ADAO and its potential for growth and community development. Organizational autonomy suggests the importance of networking, as collaboration is central to the development of both individual and group identity. However while the ADAO is effective in developing relational autonomy competency amongst its membership its capacity for organizational autonomy competency is not as well developed.

Chapters five, ‘body’, and six, ‘mind’, illustrated how the ADAO is connected to regimes of governmentality that influence clinical service provision. This chapter aimed to show how the ADAO is also engaged in a process of resistance to the model of the healthy citizen. The chapter has reflected more critically on whether the ADAO replicates the dominant normative discourse of the healthy citizen discussed in chapters ‘body’ and ‘mind’, or is actively engaged in the construction of a different kind of subjectivity. The relational autonomous self poses a challenge to the model of the healthy citizen whose

autonomy is contingent on containing the 'unstable body' through the mastery of a 'rational mind'. The ADAO's focus on relational autonomy signals a movement away from the healthy citizen towards a model of personhood based on connection rather than separation, interdependence rather than independence. In so doing the lived realities of anxiety sufferers become more apparent and more central to well-being and the development of personhood. If we are to understand citizenship as a participatory process then the model of the citizen upon which citizenship is based must be understood relationally, rather than as atomistic. In this way the ADAO's focus on relational autonomy and sociability becomes the basis upon which active, deliberative, participatory democratic forms of health citizenship can develop.

The ADAO's focus on lay knowledges, and the importance of communicating those knowledges to a wider public is motivated by a need to address and understand the lived conditions under which people with anxiety conditions live. The ADAO seeks to inform others of those realities, and assist those affected by anxiety conditions, thereby reducing potential forms of oppression and marginalization. In this way the ADAO's focus on the first hand experiences and knowledges of those affected by anxiety conditions is necessary to foster health citizenship. The ADAO needs to, and has something to, contribute to the development of an effective politics of inclusion and active forms of citizenship, rather than simply reproducing other discourses. The ADAO needs to exist as a legitimate option for sufferers that allows for the possibility of discussion and action informed by suffers and that privilege sufferers experiences.

These issues are advanced in the next, and final, substantive chapter. The following chapter, chapter 'breath', like this one, is also concerned to explore relational aspects of subjectivity and identity, but does so through issues of community and citizenship. 'Breath', brings together arguments from all the previous substantive chapters, including this one, to further understand what is necessary for the development of health citizenship in the hopes of creating an effective politics of inclusion and diversity.

Chapter Eight – Breath: Spaces of citizenship - connecting the organization

“Breath is interesting in that it is what connects us, it’s one thing that connects us to the outside and inside, and so just that experience of the focus on the breath, is automatically connecting you to your inside environment and what it feels like to breathe, and taking in air from the outside, with every breath, and that is a way of connecting. Boundaries, that’s the way that comes up. Respecting one’s boundaries is something like communication...but those boundaries move. They help us communicate and connect us to others. It’s through that that people start to understand that we all experience similar things. Often people with anxiety feel very different from others. We usually have two or three people with intense anxiety and feel really totally different, and through the group [they] really find that anxiety is part of the continuum of what people experience. It gets extended to, it’s about being human, it is the human condition” (Kim).

8.1 Introduction

A point of agreement within clinical and non-clinical discourses on panic, anxiety and agoraphobia is that breathing control is key to the management and well being of persons with panic. The focus on breathing exercises initially came from outside the western ‘clinic’ and is emblematic of the influence of ‘alternative’ or ‘holistic’ health practices upon which the ADAO draws. Like ‘heart’, ‘breath’ is also a metaphor of intersectionality and intersubjectivity. But, whereas ‘heart’ alludes to the relations between of self, identity and community, the metaphor of ‘breath’ draws attention to the mutually constitutive and negotiable boundaries between inside and outside, public and private, self and other, identity and community (Code, 2000).

This chapter explores how the ADAO negotiates the boundaries to which the metaphor ‘breath’ refers, and how, in so doing, it creates its own spaces and sense of identity and community. I argue, that these processes are connected to a strategy of promoting health citizenship as opposed to the model of the healthy citizen. Two interconnected aspects characterize health citizenship. First, health citizenship entails the integration of lived realities of ill health, disease and disorder into a model of the citizen-subject as an important part of what constructs (rather than undermines) people’s identities and subjectivities. Second, while health citizenship involves the creation of ‘new’ spaces and places of citizenship, it also remains in dialogue with dominant, normative clinical concepts and spaces of citizenship.

A central aspect of health citizenship is its connection to the politics of difference and the

ability to create spaces in which diversity is possible and encouraged. These spaces of difference help challenge simplistic understandings of subjectivity and community, and challenge simplistic mappings of the public and private onto specific places, activities and persons. If community is understood to be an expression of diversity rather than homogeneity, then community development is a process in which difference and multiplicity is central. If community development is understood to be a form of active citizenship, then citizenship is not about replicating the subject but about celebrating a diverse range of subjectivities that form a collectivity. The focus on community development as an active form of citizenship highlights the importance of sociability and group identity within health citizenship.

Chapters five, 'body', and six, 'mind', elaborated how the ADAO adopts, resists or negotiates normative versions of the citizen-subject, and chapter seven 'heart' illustrated how the ADAO moves beyond normative understandings of the citizen-subject as individualistic and autonomous, to refigure citizenship as relationally autonomous. Taken together, these chapters have shown how the ADAO creates a figural space for itself within Ottawa that acts as an alternative to other service providers, and actively moves away from the model of the healthy citizen towards health citizenship.

In this chapter I build on this analysis by exploring more closely the spaces and places of health citizenship constructed by the ADAO. While chapter seven focused on the relationship between health citizenship, subjectivity and identity, this chapter focuses on social dimensions of health citizenship, implicated in the creation of community. This chapter focuses on two differing yet connected ways in which health citizenship provides a structure for the creation and negotiation of difference. First, in section 8.2, I focus on the antagonism of the radical citizen; and second, in section 8.3, I explore how community development, as a form of citizenship in action, is connected to the politics of difference.

To this end I draw on complementary theorizations of citizenship. First, I use Michael Brown's (1997) reading of Chantal Mouffe's (1992, 1993) analysis of radical democracy to explore how the ADAO's volunteer companion program redraws traditional boundaries between state, civil society and family, and between public and private. I then turn to Ruth Lister's (1997) account of citizenship, Iris Marion Young's (1990; 1997) reconceptualization of community and Staeheli (2003), Moore and Wismer's (1994)

account of the work of community to show how the volunteer companion program deploys diversity as an integral element of health citizenship.

8.2 The volunteer companion and new spaces of citizenship

8.2.1 Spatializing radical democracy – introduction to Mouffe and Brown

According to Mouffe (1992; 1993) the key for democracy is an antagonistic and anagonistic moment, where anagonism means that one strives for effect and material change in people's lives. Radical democratic politics is based on an antagonistic pluralism- the constitution of collective identities around clearly differentiated positions that allow us to apprehend the multiplicity of forms of subordination that exist in social and political relations. In other words radical democracy works by utilizing antagonism as a medium for change and creates conditions in which anagonisms can be heard and translated into new egalitarian social relations, practices and institutions. This radical pluralism allows for the articulation of different democratic struggles and the choosing between "real" alternatives that create new spaces of citizenship (Mouffe, 1993).

The pluralism advocated within a radical democratic politics involves acknowledging the contingency and ambiguity of identity, as well as the constitutive character of social division and antagonism (Mouffe, 1992:13). Mouffe conceptualizes the social agent of citizenship as the articulation of an ensemble of subject positions corresponding to the multiplicity of social relations in which s/he is embedded (Mouffe, 1993:82). Those subject positions are constructed within specific discourses and always precariously and temporally sutured (Mouffe, 1992:10). In this way Mouffe works within a framework of diversity and recognition of difference. For Mouffe however any final realization of democracy and its closure is impossible. As a result Mouffe focuses on what she describes as the political rather than politics. For her politics refers to situations where people collectively struggle towards a common end, what makes those situations political has to do with the way in which those struggles occur (Mouffe, 1993 in Brown, 1997:156). In this way the political and citizenship is a process of constant development and negotiation.

Michael Brown (1997) develops Mouffe's work within his own on radical democracy. Brown's work is inspired by Mouffe's guiding principle that we should investigate new spaces of radical citizenship (Brown, 1997:24). However as a geographer Brown

describes how Mouffe's discussion of the places and spaces of citizenship, where space is metaphorical rather than constitutive of actual geographic locations or imagined geographies, is incomplete and problematic:

"What is bothersome about Mouffe is that her writings are only meant to convince the political theorist to rethink the subjects of radical democracy- not the locations for them. While many of her arguments may seem to show a more geographical sensitivity to citizenship they actually appear to be rhetorical metaphors aimed at decentering the subject of radical democracy. I worry that Mouffe is only using the word "space" metaphorically as a gesture to widen the array of decentered social identities that come to mind when we conceptualize the citizen. Radical democratic thinking never seems to consider that citizens are always engaging in politics in actual locations"(Brown, 1997:13).

In spite of her advocacy for 'space' in political theory, the actual geographies of Mouffe's political spaces remain uncharted (Brown, 1997:4). Thus, Brown's project is to extend Mouffe's work by including a geographical analysis within a radical democratic project. He does so because the ways in which radical democracy is constituted within and by spatial relations are central to the articulation of radical democracy and notions of citizenship. If citizenship is opened up to multiple social identities and social relations it has not been previously associated with, then we must also open it up to a wider variety of material spaces not previously considered political. Brown wants to enhance a radical democratic project by demonstrating spatial aspects of its framework and how citizenship is affected by, performed, and created within various spatial contexts. Brown is concerned to discover where the citizen, defined as the political individual claiming rights, duties, responsibilities, and membership in a political community is located. Mouffe argues that we often look for new spaces of citizenship in order to reject modern, foundational, and fixed axes of politics. Yet, it is not enough to look for new spaces and leave the old ones behind, we must look at how various geographies are being redefined.

For Mouffe and Brown the civil society holds a potential for radical democratic citizenship as a "new space of citizenship" (Mouffe, 1993). However unlike Mouffe who sees the state and civil society as distinct, Brown views civil society and voluntary/third sector as a crucial element of state and public restructuring. For Brown the third sector acts as a "shadow state" that complicates any simple geography of the public sphere (Wolch, 1990 in Brown, 1997:19). The implications of this relationship for citizenship lies in situating relations of the political process not merely in public places of the city but also in the grassroots community organizations that bring strangers together through

common, voluntary pursuits (Brown, 1997:22).

New spaces of citizenship imply new spatial interactions between state and civil society (Brown, 1997:85). Thus, organizations such as the ADAO occupy a new space of citizenship between the state/clinic and civil society. The ADAO, like the AIDS groups Brown discusses, fosters radical democracy by institutionalizing citizen's obligations towards one another and by affirming the equality of rights to which all members of a given political community are entitled (Brown, 1997:106). Brown focuses on the role of the 'buddy', similar to the ADAO's volunteer companion, as a new site of radical citizenship. He demonstrates that buddying is a form of citizenship defined through locations where elements of family, home and state/clinic relations are combined in places across the city.

8.2.2 Introducing the volunteer companion program

Traditionally volunteerism has been connected to citizenship when volunteer activities are placed within the public sphere. However, within the private sphere volunteers are positioned as carers, as friends and as assistants separate from civic duty. In his book *RePlacing Citizenship* (1997) Michael Brown challenges and complicated the relationship of the public-private divide and volunteerism through concepts of radical democracy. Brown identifies how ACT-UP, a self help organization for people living with AIDS, creates spaces of radical democracy in two primary ways, by blurring the division between state and civil society; and by blurring the boundaries between state and the home. This section furthers Brown's discussion of radical democracy by demonstrating how the boundaries between home, civil society and clinic (which is linked to the state), are negotiated within the ADAO's volunteer companion program. In this way the volunteer companion program is implicated in the re-mapping of what is considered public. This "fuzzy geography" reflects "the multiple social relations characteristic of radical citizenship, empowers volunteer companions to meet their obligations as citizens, and empowers clients who are entitled to support as citizens of a political community" (Brown, 1997:123).

As discussed in chapter seven, 'heart', and in chapter four, the volunteer companion was the first program set up by the ADAO, when it was still the APVA. The program was the first of its kind in North America offering home support for agoraphobic individuals from

non-clinical experts. The volunteer companion provides both practical and emotional support for agoraphobic individuals who need assistance in becoming more mobile. The volunteer is there to assist the agoraphobic individual in setting and completing a list of goals outlined and developed at the beginning of the volunteer companion relationship. The volunteer is presented with a volunteer companion training manual/handbook and must attend a series of courses provided by the ADAO on the volunteer program. The program is goal oriented, but in practice goals may take a long time to achieve and thus the program is much more focused on creating alternate support structures for the client that encourage well being. According to the volunteer workbook/training manual the role of the volunteer is to support their client physically and emotionally; help them through a panic attack or any other physical or emotional change; and to help set goals with the client (APVA, 1998c:8-11). The program has always had a much longer list of clients than volunteers. Yet, in spite of high demand the ADAO matches anyone who applies to the program with a volunteer, and actively advertises for more volunteers as demand for the program increases yearly. Volunteer companion matches are continuously evaluated and have a trial period of three months. If after that trial period the volunteer and client would like to remain matched, the volunteer match continues for at least another 6-month commitment. If the match is not successful for any reason at any time, the client or volunteer can stop the match and ask for a new one.

Volunteers and clients are matched according to their interests, the areas they live, age and the intuition of the volunteer coordinator to determine who will work best with one another. Volunteers and clients are at first strangers. This means that people who would have ordinarily never associated with one another due to race, class, ethnicity, age, and other characteristics are made to collide because of the public dimension of the volunteer companion relationship (Brown, 1997:149). This is an example of the agonistic nature of the volunteer companion program, where people from different backgrounds come together, without suppressing their differences, in a useful and helpful coalition that is empowering for both the client and volunteers.

8.2.3 The volunteer/ client relationship

8.2.3.1 (Inter) dependency

Providing support to clients is one of the central aims and goals of the volunteer companion program. This process of offering support can become problematic when the

volunteer's and client's expectation of what constitutes support is different from one another. The support can be emotional, for example discussing personal issues, listening, talking and spending time with the client. The support can be practical, for example helping the client with errands and goal setting. However, providing practical support can become a problem when clients expect their volunteer companions to be "cleaners, chauffeurs, and babysitters" (Michelle).

"To be honest my first volunteer experience was a disaster, the first thing was I think she did not have a full grasp of what the program was and as a consequence she wanted me to do things I did not necessarily want to do, such as: take her to the doctor, be on twenty four hour call when she needed someone to pick her up and take her places. I don't think she had a full grasp of what I was required to do. I didn't meet her needs, so we had a breakdown in communication" (Amy).

For clients practical support becomes a problem when volunteer companions expect "too much of their clients" (Angie), expecting clients to progress within the volunteer's time frame rather than the clients.

"I approached my client with vim and vigor, anxious to change the world and help, and this lady was completely handicapped. I could not help her. I tried. I would go over all the time and play scrabble or whatever, and I tried to use my training to work on things, but she was not interested, and with her fibromyalgia she could not do the things I wanted. I wanted to practice letting her off on the sidewalk and just going to the park but she couldn't stand well. I stressed her out more" (Alexis).

Often problems result because the volunteer wants to achieve quick results, which in most cases is neither practical nor possible. Relations and expectations of time and space within the volunteer companion relationship mean that patience is a necessary skill. Problems also occur when the volunteer oversteps her/his role and acts authoritatively as a counselor, social worker or therapist. These are roles that many volunteers initially want to play, but that changes as the relationship progresses.

"I am there to support her, and to be non judgmental and to help her reach her goals that are set out monthly, not to become her friend or her therapist... there are certain ground rules... I am there for her to accomplish her goals and help her be healthier... not to give her therapy" (Heather).

There are points where the boundaries of the volunteer companion-client relationship become obvious and enforced. Companions cannot always help their clients with their problems at home or with dysfunctional personal and family relationships. The volunteer is encouraged to remember that the homescape of the client is to some extent a private

space they do not have access to.

8.2.3.2 (Dis) empowerment

While most volunteers and clients describe the enabling and empowering aspects of their volunteer experiences, there is always the possibility of disempowerment in volunteer companion relationships. As one interviewee notes “volunteers tend to be rescuers which can create dependency, that is something that has to be worked on in training” (Emily). Certain clients become dependent on their volunteer, moving their focus of dependency from a family member or clinician to the volunteer. Conversely, clients are afraid their dependency on their volunteer will become a burden for the volunteer:

“She [the client] does rely on our weekly get together, not just to go out and do things but also to talk. And now she knows if she needs to come over she can, whereas before it would have bothered her. She did not want to bother me. She did not want to bother anyone. She did not want to feel that way, and she was afraid she would be a user all of the time. And now I want to do things for other people, she has that need. I think she is still afraid I will think she is a user and that she needs me” (Hannah).

Individuals volunteer for a variety of reasons which include: feeling they are making a difference, feeling better about their own lives, creating friendships; and making connections within the ‘community’. Clients want volunteers for similar reasons: to enhance their well being, to feel accepted, to establish friendships and meet new people. But often expectations of volunteerism outweigh the experience of volunteering. Thus while a celebration of the volunteer companion program is important, an uncritical view of volunteering can lead to problems and false hopes for both client and volunteer. Being a volunteer may not always be a rewarding experience. Volunteers sometimes feel they are in a position where they must monitor or “spy” on their client, which places them in an awkward position. Some volunteers do not see their clients improve, which is both frustrating and disempowering for the volunteer (and client) who feels that s/he has failed as a volunteer. Because many people volunteer to feel that they are making a difference in other people’s lives, not seeing improvement can be disheartening and disempowering. Discussing these pitfalls of volunteerism is an important aspect of volunteer companion training that is more likely to result in a positive volunteer relationship, thereby encouraging aspects of citizenship, rather than discouraging both volunteer and client from future volunteerism.

8.2.4 Volunteer companions and the development of community

One of the motivating reasons for clients and volunteers to enter into and use the volunteer companion program is to feel a part of a community and develop networks of affiliation in order to socialize. A sense of community is developed within the ADAO because volunteers are celebrated and made to feel as if they are an important part of the organization through volunteer appreciation days. These appreciation days involve social activities, and the presentation of awards. This enhances volunteers' connections to the ADAO and makes them feel as if they belong to the wider ADAO community. Some interviewees, who were very appreciative of volunteer appreciation days and the sense of community it engendered, expressed a desire for more events where volunteers and clients could get together and socialize, thus further enhancing a sense of community and involving clients in the activities of the ADAO. Volunteer appreciation days could be understood as a part of the ADAO's contribution to developing community.

"Both volunteers and clients in the program want a sense, as I did, a sense of community. I think they develop a sense of community, a sense of getting support from the volunteer, listening to other people's feelings of isolation, and are really beneficial. I think it gives them hope. I joined the ADAO because of the sense of community I felt when I volunteered. Cheryl has volunteer appreciation day parties, that have brought some of the volunteers together because otherwise we're in our own separate, separate little worlds" (Lauren).

The development of the ADAO's community is also fostered because many clients and volunteers want to give back to the ADAO and their other communities. Volunteers and clients have gone on to take up positions within the ADAO or to act as volunteer companions themselves. For volunteers the program made them feel as if they should become more involved within their wider communities and more involved in other programs within the ADAO.

"After being a companion I wanted to join more affiliations within and outside of the ADAO. Like the fourteen-week program or newsletter...I wish I would have gotten more involved that way... I really wanted to be a part of the community... That's why when Cheryl offered me the chance to work with the kids I did" (Maria).

8.2.5 Volunteer companions and daily geographies

The volunteer companion program's purpose is to extend the spaces of the ADAO into

the daily geographies and private sphere of agoraphobic clients, to extend the sphere of influence of the ADAO, and to introduce clients to the multiple spaces and places of the ADAO. Client's homes become extensions of the ADAO and the ADAO is brought into those private spaces by virtue of the connection between organization, volunteer and client.

The volunteer companion program helps to blur and recreate the spaces and meanings of private and public. The process of trying to encourage clients to be more publicly mobile was frustrating for many volunteers because the spaces they understood to be public, were not necessarily the spaces that clients understood to be public. The division of public/private into binaries is problematic because public/private spheres and spaces cannot be neatly separated as oppositional or directly associated with private or public activities (Killian, 1998; Kumar, 1996; Light and Smith, 1998; Weintraub, 1996; Weintraub and Kumar, 1996). Private activities and relations of privacy often take place in the public sphere, conversely public activities and publicity is a component of the private sphere (Bell, 1995; Bondi, 1998, Howell, 1993; Squires, 1994; Staeheli, 1997). For example, when a neighborhood park initially thought of as public became the site of an intimate private conversation between client and volunteer the perception of that place as public changed, establishing it as a private personal safe place for the client. In this way both clients and volunteers learn to re-map their concepts of what is public and private. For some clients getting to the edge of their driveway is significant progress. For a volunteer the edge of the driveway may at first be viewed as part of the home space as private property, but then is transformed into a space understood as part of the public sphere.

"You forget you don't realize how far some things are. The front step is a long way for some people. It took her a long time to get to the corner of the street. What you take for granted as being safe or part of your home isn't for some people, or that spaces like a park can be the best places for an intimate conversation. You just stop taking some things for granted. I don't see Ottawa in the same way; I look for different things now, things that might make someone anxious. When I go to Confederation Park, I think of the talk we had how it helped her, I don't think of all the people. But then I remember this is a park with lots of people in the middle of tourist land, I've seen fireworks here... it's a big public "Canadian" touristy place... but it isn't just that anymore" (Hannah).

Volunteering takes place not only in private sphere, but also through relations of privacy and intimacy, often located within public spaces across the city. Public spaces are sometimes best situated for the development of intimacy and privacy between volunteer

and client because of problems within the home and because within their homes clients do not feel they can talk freely. Public places may provide private spaces to converse, while private settings may become spaces of public spectacle and family argument.

The client's needs and goals are the defining elements of the volunteer companion relationship. Those goals and needs dictate the form that support takes. Because those goals and needs are located within or near the client's homes, volunteer companions act as citizens in the private sphere. Clients themselves should be understood as radical citizens. First the support they receive is provided to them on the grounds of need rather than bureaucratic policy, which for many is a more satisfactory politics (Fraser, 1989; Lister, 2001). Second, it is through the process of companionship that the client is able to become more mobile, access more public and private spaces and recreate their sense of what is public and private, safe and unsafe.

“They [the volunteer companion] are there to support you and help you get out and expand your safe place so you feel safe in the world and not just your apartment. I mean for me the grocery store was a problem. First I had to take a bus, which I could not do because of all the people I thought they were looking at me, then the store, same thing, and its hard to get out of. But we would go on the bus, and we would chat in a seat, I would focus on her, we'd have our own private space on the bus with all the people there. The same for the grocery store. It made them safer; I got past the anxiety thing with her there” (Samantha).

The shifting patterns and types of support provided by volunteer companions underlie a characteristic of radical democracy: that citizenship is located in both public and private spheres. The interaction of the volunteer companion and client within various geographies helps to define what is understood as public and private by both client and volunteer. Citizenship is not limited to being in public spaces, but is understood as a process of belonging and feeling connected to place, which involves the ability to inhabit and move freely within public and/or private spaces. In this way the volunteer companion program is an important form and vehicle of citizenship that helps to create a sense of place and the creation of safe spaces.

8.2.6 Volunteer companions and the spaces of citizenship

For Brown buddying, or being a volunteer companion, fits with Mouffe's discussion of radical citizenship in three ways. First the lack of recognition of panic and agoraphobia by the clinic/state, state in particular, exhibited by a lack of services helps to define a

political dimension of volunteering. Additionally many of those who are agoraphobic often exist in antagonistic relationships with their family and the clinic.

“All her daily requirements were met by her husband, and this was the problem. He resented her tremendously... besides the isolation that she felt, she had no girlfriends, she had no one around her except her husband, crotchety old man... so that was even more depressing, and made it more depressing for her. So the lack of self esteem as well as a lot of verbal abuse in the relationship. It absolutely contributed to it [the agoraphobia]. And although he resented it, he enabled her in her illness, because if she wanted to do anything, he wouldn't allow it, he would say, no, no, no, I'll drive you (laughs). He's very dramatic” (Michelle).

Volunteers are there to assist the client in ways that their families cannot and the state will not. This defines a political dimension of the volunteer companion, as volunteer companions exist because that antagonism exists. The existence of the volunteer companion is predicated upon the antagonistic relationships clients have with failed support networks. Often volunteer companions are welcomed precisely because they are not family, and the ‘impersonal intimacy’ of the volunteer companion relationship makes the client feel unencumbered, more able to detach themselves from their current stifling surroundings (Rooney, 2002). There are some clients who are not interested in developing a relationship of intimacy with their volunteer, and some volunteers who do not want to be intimate with their client. These clients use the volunteer as a watchdog monitor who ensures through their ‘public’ viewing and bodily presence that the client achieves their goals. In this way the volunteer companion acts as a public figure brought into a variety of private spaces. The volunteer companion is situated within a network of other familial relationships that reinforce and reflect new forms of family and the definition of “home” (Brown, 1997:136). Thus, in examining volunteer companion relationships the geography of where citizenship occurs needs to be widened to include spaces of the family and ‘home’.

Second, volunteer companions strive to make a difference in their clients’ lives by offering support.

“We were going from week to week and every week we got a little bit further. We made it around the block and we finally went into a coffee shop. And she felt really good about herself when she did that. And we continued, as a result of this she started to feel a change within herself and she started wanting to be more independent, and she told me that sometimes she would like to do this by herself. She'd like to go outside to the coffee shop and go and do whatever, maybe. And she got stronger that way. And I had to sit back. And then every time I went and saw her, she seemed a bit better and you know I was very happy in the beginning,

but then it's like she flew on her own and she just went off and it was great. She started becoming a lot more independent" (Maria).

Third, volunteer companions and their clients embody a "de-centered subjectivity" another way in which they become radical citizens (Brown, 1997:129). Agoraphobic clients generally do not fit within classical definitions of the citizen. Clients of the ADAO are often women who have multiple illnesses and disabilities, and generally avoid public places and the public sphere. Additionally as many volunteer companions have been agoraphobic themselves, or have suffered other ailments and illnesses, these companions like their clients do not comfortably fit into classical definitions of citizenship. The volunteer companion defies fixed definition and subjectivity, because many of the volunteers have been former clients of the program themselves and because being a volunteer involves a wide variety of social relations and positions.

8.2.7 Section summary

Section 8.2 has illustrated the ways in which the volunteer companion program could be understood as a form of radical citizenship. This is important because health citizenship is often positioned in antagonistic relations to the state and clinic. Health citizenship should be thought of in terms of an alternative or antagonism to the dominant model of the healthy citizen upon which much clinical and public health services are based. In order for radical democracy to be an example of health citizenship, as it is with the volunteer companion program, it must offer an alternative that more clearly addresses the lived realities and needs of those with anxiety conditions. Because the volunteer companion program is client directed and sufferer led it is more conducive to addressing the needs and desires of those who are agoraphobic, not offered by other service providers, thus offers a better model of health citizenship.

Unlike the buddies Brown describes, volunteer companions do not have to deal with the impending death of their clients. Unlike AIDS buddies, most volunteer companions see their clients getting progressively better, thus there are significant rewards for both client and volunteer from the volunteer companion process. Many volunteer companions have remained with a client for many years, and after the client no longer needs the volunteer a friendship still remains. The volunteer companion program highlights how private relations of support are political acts that contribute to the construction of citizenship. Not having this support exacerbates the clients struggle with their anxiety condition and

places them on an unequal footing with other members of the community. Ultimately, the volunteer companion program strives to make changes in both clients and volunteers' lives:

“People volunteer to feel needed, valued or have social contact as well, so the volunteer program is a benefit, it's a very healthy benefit. It made me feel connected, especially because I am new to Ottawa, I felt connected to the city” (Maria).

The diversity of locations in which the volunteer companion program is exercised enable relations of citizenship to emerge in the volunteer companion relationship. For volunteer companions like buddies “just being there” does not mean just being anywhere (Brown, 1997:154).

8.3 Community development as health citizenship.

8.3.1 Introduction

This section expands on the discussion of health citizenship and radical democracy in the previous section by exploring how the volunteer companion program is an example of community development, what Ruth Lister (1998) describes as citizenship in action. The volunteer companion program is one example of how the ADAO is involved in a process of developing and negotiating community. The theorists I draw upon within this section understand community as an expression of diversity rather than homogeneity.

Community development is a process in which difference and collaboration are central. Thus if community development is thought of as a form of active citizenship, citizenship itself is also a process of creating and celebrating a diverse range of subjectivities within a collectivity, rather than a process of replicating the subject.

8.3.2 Community and the politics of difference

In her book *Justice and the Politics of Difference* Young (1990) critiques a vision of democracy modeled on face-to-face relationships that are assumed to be transparent and translate into an immediate mutuality. She expands on this critique throughout her writings on the politics of community (Young, 1997; 2000). For many her discussion of community offers a better model of community and inclusivity. It is an approach to community that honors the desire for mutual belonging and recognition without reifying community as an ideal (Hirschmann and Di Stefano, 1997:9).

According to Young the model of face-to-face relationships is predicated on the 'ideal of community', an ideal that denies both differences and the basic asymmetry between subjects (Young, 1990:231). Community becomes problematic when its model is based on the "co-presence of subjects" that mandates self transparency and transparency to others (Young, 1990:235). Thus Young argues that the idealization of community privileges unity over difference thereby facilitating social exclusion and divisions (Young, 1990).

As an ideal, community is internally defined by its members on the basis of shared experience and common interpretation (Stanley, 1978 in Phelan, 1989). In this way community becomes a form of commonality, a group whose common characteristics and common identity preexists its members as essential attributes. A definition of community as "the common" is one in which identity is consolidated and internal to the group rather than "in common", a definition of community that advocates a framework for both the deconstruction of identities and the representation of the group. This latter framework is identified within feminist theory as a diversity perspective, which is the framework Young works within (Young, 1991). Diversity perspectives go 'beyond' equality perspectives that argue for integration into existing structures, and beyond difference perspectives that seek to privilege the subordinated and marginal. Diversity perspectives deconstruct the division of equality/difference itself (Bock and James, 1992). As Grosz argues the "issue for diversity theorists is not to privilege one term at the expense of the other, but to explore the cost of their maintenance" (Grosz, 1994:32).

For Young what makes a group or community is not internal to the attributes and self-understanding of its members but relation in which it stands to others (Young, 1997:389). Community, or social groups are not limited to the commonality of persons who seek a particular goal, or desire the same policy, or share similar political beliefs - shared interest alone is not sufficient to constitute a social group (Young, 1990:186). Young is not suggesting that community is not connected to internally defined meaning, but rather that people within the community are more than just the group and that the identity politics of community often rigidly defines and limits individual and group identity (Squires, 2001). Group representation, or 'community', does not have to be centered on an interest or identity based conception of community that focuses on the politics of inclusion/exclusion and equality/difference. Communities can organize around 'identity

politics' but shared experience is not an automatic guarantee of community, as there is always diversity and disagreement within any community or group (Phillips, 1995).

Young's critique of the ideal of community is a commentary on the nature of justice within contemporary democratic models. Young's thesis is a critique of the ideal of impartiality and a unified polity that she rejects on the grounds that it promotes the particular standpoint of the privileged as if it were a universalist standpoint, thereby legitimating the privileged and invalidating as partial the viewpoints of the oppressed. Instead she argues that a conception of justice, which challenges institutional domination and oppression, should offer a vision of a heterogeneous public that acknowledges and affirms group differences (Young, 1990:10). To achieve this a democratic public should, she contends, provide mechanisms for the effective recognition and representation of the distinct voices and perspectives of those of its constituent groups that are oppressed or disadvantaged (Lister, 1997:78).

Politics, like community, needs to be conceived of as a relationship across time and space of strangers who do not understand one another in a subjective and immediate sense (Young, 1990: 233-4). This is important because when 'community' and politics appeals not just to what is "in common" but to "the common", or sameness the "closure of the political" is imminent (Nancy, 1991). Young's work stresses the importance of attending to the social relations that differently position people and condition their experiences, opportunities and knowledge of society rather than simply formally including all affected individuals in the same way (Young, 2000:83). Communities are not heterogeneous entities or distinguishable 'things' but a diverse political process of interrelationships and networks of individuals and groups. Therefore for Young, drawing on a deliberative democratic tradition, collaboration, participation and partnership are more integral to an understanding of community (Squires, 2001). Community needs to be directed towards deliberation with other social groups in the hopes of creating a metaphoric and actual space of reciprocity between various interests.

8.3.3 Community development as active citizenship

Ruth Lister's theorizing of citizenship is based on Young's discussion of community as a destabilizing force that brings us face to face with multiplicity and difference, rather than community as a homogenous entity that serves to delimit the way in which we understand

ourselves and interact with others. Lister's work on citizenship, similar to Young's work on community, challenges the way in which community is idealized as a natural phenomenon of similar people who are coming together. Thus, Lister's vision of community as a form of active citizenship is a vision of bringing together people with different identity politics through community development (Lister, 2001; Young, 1997). Community is about the negotiation and creation of difference and celebration of diversity.

The gathering together of people who may come from very different places and positions and who share a set of goals and aims was a common way that interviewees described why the volunteer companion program helps to develop the ADAO's community. The volunteer companion program necessarily highlights the way in which people with different experiences, viewpoints and to some extent different goals can come together to form bonds of community.

"On the whole my volunteer experiences have been with clients that I was very different from, but that did not matter... But with many of the clients, through the program, we developed a friendship that we have continued even after the match was over, and she did not need my help. We still go to the movies, and sometimes I have lunch at her place... what is amazing is that she wants to be a volunteer now, she feels well enough to help someone like I helped her. The experience really connected me, and I think she felt connected, to the ADAO, it's become part of her, of both of our communities...we both tell everyone about our experience with the program and recommend it to anyone we know...that connection and appreciation she has for the ADAO is why I think she wants to be a volunteer" (Anne M.).

Lister (1997) focuses on how community is both internally and externally differentiated, defined by both what is inside and outside of it. Thus, any community is comprised of a wide range of voices and perspectives that help shape its content and form. In this way Lister argues first; like Mouffe that all communities have an antagonistic function, that the political process is an always ongoing process of negotiating difference; and second, like Young that community has an integrative function that allows us to network with others at the same time as it forces individuals and groups to think about issues of positionality. In combining both Young and Mouffe's work, Lister (1998; 2001) highlights how citizenship can act a force of inclusion as well as exclusion. Through community development a group or individual may come to realize their lack of place within the wider political and public sphere. An experience felt by volunteers and clients at times while trying to access resources and work through various client goals.

“The volunteer program is there to help them overcome whatever they are dealing with...I think that is very important and that is what makes it a community. But I have been disappointed because I try to help her, things she wants help with and they (outside resources) are not there for us, we have to make our own places, we have to be even more resourceful to achieve her goals” (Lauren).

What is most central for Lister is that community development needs to be understood as a form of citizenship in action, a central political act that connects both individuals and groups together and to the state (Lister, 1998). Thus, rather than viewing community as a background for politics, community becomes the basis for politics (Phelan, 1989).

According to Lister citizenship and community are linked because both are seen to be process involving political participation and a status involving rights. She identifies two main citizenship traditions – civic republicanism where citizenship is understood as a status involving rights, and classical liberalism where citizenship is understood as a practice involving political participation. For Lister these traditions combine to provide a framework in which women’s actions and activities within spaces and spheres not traditionally thought of as political, such as community, can be seen as a form of active citizenship (Lister, 1997; 2001). By extending the realm of the political to include community development, Lister is suggesting, like Brown, the importance of looking for new spaces and subjects of citizenship, spaces that have historically been de-politicized and thus marginalized or privatized.

The ADAO, through programs such as the volunteer companion program help create these new spaces of citizenship - it is an important actor involved within a wider network of political action. Lister’s linking of community and citizenship suggests that programs such as the volunteer companion program are political processes that connect individuals within the ADAO to one other, and that also entitle those individuals to engage within the public and private realms of the clinic/state. Because the volunteer companion program is directly involved in the re-creation of agoraphobic spaces, geographies that have historically been isolated and excluded from the public sphere of political participation, active citizenship is extended to people and places it had not been before. Additionally, development of the ADAO’s community, though the volunteer companion program allows for the articulation of experiences that have previously been marginalized and silenced. The ADAO’s community development process not only brings to light the lack of voices and experiences of anxiety sufferers, but the lack of places for persons with anxiety. The volunteer companion program seeks to repair that lack by extending

potential spaces of community for agoraphobic individuals who have avoided the public and private spaces in which community is negotiated. A central purpose of the ADAO, as suggested by their mandate, is to connect sufferers to each other and to a wider public in different ways. As one interviewee discusses: "it is very important to connect people, especially people who are restricted in society and who have limited freedom, connecting them more to the community in everyday ways" (Olivia). In this way the ADAO acts to support a wide range of individuals and their families. This encourages people to be involved in a range of other relevant communities and those wider communities help to shape the identity and boundaries of the ADAO.

Community development as a form of active citizenship should also be seen as "community work" (Milroy and Wismer, 1994). The term community work acts as a new conceptual framework that highlights the limitations and inherent contradictions of conventional private/public formulations and women's places within those formulations (Milroy and Wismer, 1994). Community work is a term for "the work that women (and men) do outside of their homes and paid working hours, and within their localities" (Milroy and Wismer, 1994:72). This definition is limiting and problematic when thinking about the ADAO for two central reasons. First, many members, including the executive director herself, are agoraphobic and housebound and cannot work outside of their homes. Second, the volunteer, client and the ADAO are all involved in the community work that helps to expand and develop the ADAO's community. What is useful about Milroy and Wismer's notion of community work is their description of it as maintenance work- part of the social glue that holds people together. Community work is essential for the building of networks and connections between individuals and groups that help to dissolve the bipolar way in which the terms 'public' and 'private' are used (Milroy and Wismer, 1994).

Understanding community development or community work as a form of citizenship is important as community is a part of the debate within western countries about the social rights of citizenship (Staeheli, 2003:816). In one sense this has to do with a context of shifting national and economic conditions in which service provision is being transferred from public health agencies and the state to 'communities' themselves (although the extent to which those communities are still directed by public health institutions is a important issue) (Staeheli, 2003:816). In another sense this has to do with the use and idea of community as a means of establishing social change, and as a basis for building an

inclusive society in which social justice can be achieved (Staeheli, 2003:816).

Community, thus, becomes a space for political and social change. Often community development is viewed as a political process, through a focus on empowerment as well as educational and consciousness raising work that may lead to empowerment (Staeheli, 2003:825). Empowerment, through increased mobility is a key goal of the volunteer companion program, as well as a common response (or expectation) by both clients and volunteers who have gone through the program.

“Our goals [for the volunteer companion program] are to help our participants: understand what panic and agoraphobia are; develop coping skills; build self confidence; develop self esteem; foster independence; see themselves as right just as they are; find the appropriate help when asked; set and achieve goals; and participate in life more freely without fear” (APVA, 1998:40).

Community development is often viewed as a process of harnessing and creating social change, as a way of connecting individuals and groups, as a space of mutuality in which the development of social trust is possible. Community development, as a process of social change, is both an attempt to engender and enrich a sense of place as well as an attempt to locate and identify that community within the geographies in which it is situated (Staeheli, 2003:827). The extent to which community development does create social and political change, change that would lead to valuing inclusivity, is a central issue. However this is an issue which is difficult to answer or measure within the timeframe of the research context, and without extensive follow-up of volunteers and clients.

8.3.4 Shifting spheres - community and the public/private divide

The creation of new spaces and subjects of citizenship are connected to a repolitization and rethinking of the relation between community, citizenship and the public- private divide (Pateman, 1988; 1989). Young’s work on community is based on an analysis of modern citizenship as constructed as a separation between the public and private that presents the public as the realm of homogeneity and universality and relegates difference to the private sphere. Thus, for Young (1990; 2001) and Lister (1997) one crucial problem is that the public realm of citizenship has been presented as expressing a general will, a point of view that citizens have transcended their differences to form a common unified identity. Young argues in favor of a repolitization of public life that would not require the creation of a public realm in which citizens leave behind their particular group

affiliation and needs in order to discuss the common good (Young, 1990). In its place she proposes the creation of a heterogeneous public that provides mechanisms for effective recognition and representation of distinct voices and perspectives of groups that are disadvantaged or oppressed. In her more recent work, Young focuses on the relationship between community and positionality, which better enables thinking about groups, or community as constituted through relations among persons within various geographies (Bondi, 1993 in Young, 2000:100). For Young this means that the situated knowledge of people located in different group positions acts as a resource for increasing the understanding of a wider public that helps to promote public discussion and decision making, moving those people beyond their own parochial interests (Young, 2000:109).

Young's analysis of the public and private sphere in relation to community is extended and more thoroughly developed and discussed within feminist geography. Feminist researchers, and feminist geographical researchers in particular, argue that the public/private, community/individual coexist in complex combinations in everyday life that continually shift (Bondi, 1998; Bondi and Domosh, 1998; Duncan, 1996; Staeheli, 1997; Squires, 1994). Community is shifted between, to and from the private to public sphere depending on how that community is characterized and privileged (Shanley and Narayan, 1997). For example, when a community is not seen as 'public' it may not receive government funding, support or publicity that may be disabling and counterproductive. But, when community is seen as private it is subject to a different (often lesser) amount of scrutiny, regulation and observation that may be enabling. 'Community' is conceptualized in public and private ways that reinforce and subvert that dualism and its associated dualisms (Shanley and Pateman, 1994). As a public, community functions are action and awareness oriented; they are directed towards the creation of justice and care as community politics. The community is there to serve the needs of its groups and a wider group of individuals. Community in a public sense is about service provision; communities are accountable to the state and its citizenry. Community as an extension of the private is about relations of intimacy and friendship that develop bonds of mutuality. Community is related to the interpersonal bonds of family focused on the development of kinship and identity politics. But community work is also thought of as a process of networking and socialization that is neither simply public nor private.

The space of community development remaps the boundaries between what is public and

private through practices of care and a focus on interdependence, sociability and the relational nature of individual and group. Spaces created through community development act as a 'space of betweenness' (Staeheli, 2003) that link the public and private in a variety of ways, what Moore and Milroy describe as a "third sphere" in which new political practices and ideas more conducive to the experience of care marginalized within the private sphere as women's work (Moore and Milroy, 1994). Staeheli in her own study of the work of community identifies three ways in which community work reflects norms, practices and metaphorical locations associated with the public and private, with publicity and privacy (Staeheli, 1997; 2003). These three observations are also applicable to thinking about the ways in which the volunteer companion program as community work reflects the dynamism of the public and private, an issue discussed earlier in this chapter (see also Brown, 1997; 1999; 2003). The first has to do with the motivation for doing community work which is shaped by experiences within the personal space of the home or private as well as by experiences and structures of opportunity outside the home (Staeheli, 2003:829). This is further complicated within the volunteer companion program, as part of the motivation for the program is to reshape the private and public worlds of what is and what is not home, thus to remap private and public spaces as safe personal spaces. Second, the place in which community work is done is often in spaces that are themselves ambiguous with respect to the private and public (Staeheli, 2003:829). Third, and related to the second, "the spaces of betweenness" in which community is developed allows for a negotiation of various pressures and influences that may allow for changes within the wider society and amongst individuals themselves, connecting the public and private through the opening up of public programs and structures into the household (Staeheli, 2003:829).

Community politics can act as an alternative to state-based politics and as such are instrumental in the redevelopment of spaces in which alternatives can be heard. The association of community with meanings of the public and private sphere is about processes of inclusion, exclusion and legitimation that are racialized, gendered, medicalized and sexualized (Dwyer, 1999; Brown, 1999). What is ultimately at stake in community development is not its definition but a political struggle over power and resources (Hirschmann and Di Stefano, 1996:8). Thus the community work of the volunteer companion program is important in the context of maintaining the ADAO as a whole.

8.3.5 Section summary

This section has illustrated that the volunteer companion program is an example of how the ADAO is actively engaged in a process of community development/work that should be understood as citizenship in action. As community is about bringing diverse knowledges and people together, citizenship is also a process of recognizing and working with difference rather than subsuming difference into a model of the same. For the ADAO community development is a process that is connected to the politics of difference and creation of places in which difference is possible. These spaces of difference challenge dualistic mappings of the public and private onto specific places, activities and persons. In this way the section highlights two central aspects of health citizenship. First, the importance of diversity and difference within a model of health citizenship, and second, the potential to create networks of attachments in the form of community, thus increase the well being of individuals through those supportive networks.

The analysis of the volunteer companion program as an example of community work or community development is a project of envisioning community as a negotiation and political/social process located through geography, subjectivity and identity. Programs such as the volunteer companion program are not only examples of community development but also help the ADAO establish a sense of community, as well as, a place for itself within the wider network of service providers. The volunteer companion program highlights how 'community' is constructed within and by geographic relations of place and space connected to issues of identity and group politics. The meaning of 'community' is both temporally and spatially negotiated creating both real and imagined spaces, as well as real and imagined communities that destabilize the bipolar use of the terms private and public. 'Community' and community development forms a discursive structure of meaning within and outside of the ADAO. Therefore, community development is an ongoing process of negotiating difference and recognizing the importance of positionality. The spaces of community created by the volunteer companion program offer sufferers and volunteers viable alternative spaces of citizenship in which people can create or at least strive to effect change in the lives of those with anxiety conditions and thus work towards a model of health citizenship.

8.4 Conclusion

The discussion of health citizenship in this chapter has drawn upon various feminist, geographical and political theorists. While these theorists' commitment to a feminist politics, and the improvement of women's (and men's) lives, unifies them, there are many differences between the political traditions and contexts these authors are embedded within and the type of democracy they aspire to. Within this chapter aspects of all their work are seen as complementary in thinking through issues of health citizenship and community development/ organization.

This chapter poses the question of whether the ADAO is engaged in developing forms of citizenship that are enabling and productive for its members and for the organization as a whole. There is no consensus on a singular meaning of community, but there is general agreement amongst interviewees that the ADAO is involved in a process of community development for the purpose of creating different options and alternative spaces for those with anxiety conditions. Thus the ADAO is involved in a process of health citizenship because it highlights the needs and lived experiences of individuals with anxiety conditions and incorporates those experiences into a model of citizenship and subjectivity rather than using those experiences as something to strive against, thereby ignoring many of the realities and problems faced by those with anxiety conditions. Rather than negating one's own experience of ill health in the pursuit of an ideal of an 'able' sickness free body and subjectivity, the experience of ill health becomes a constituent part of citizenship as opposed to its antithesis.

To the extent that community, and community development is an expression of, or movement towards, social and political action, then community development is connected to health citizenship. Health citizenship is not just about recognizing and incorporating the differing lived realities of health into a model of personhood, it is about creating places in which difference is enacted upon. The ADAO strives to effect change in people's lives in ways that suggest the importance of those lives, and the need for those experiences to be counted and explored in a wider political or public forum, and it is strengthened to do so through its bonds of community.

This chapter has illustrated that the ADAO does act as a space of active and radical democracy, therefore the potential to create new spaces of citizenship exists. Yet, the

substantive section of the thesis ends on an uncertain note as to whether the ADAO will continue to create new democratic forms as it continues to expand and further negotiate the balance between maintaining its own direction and networking with anxiety service providers that are becoming more clinically oriented. This cannot be answered directly within the context of the thesis, as the question is outside the scope of the thesis affected by processes and people that are constantly changing. However, the thesis points the ADAO in a direction that may help the organization in the creation of its own space , as well as highlighting contributions the ADAO has made that can be used in order to network with other anxiety service providers on a more equitable footing. The thesis has shown the importance of health citizenship for the ADAO. But, in order for the ADAO to be an effective example of health citizenship, it must continue to create spaces in which the experiences of those with anxiety conditions are incorporated into a model of subjectivity so that they can be transformed into public awareness, education, service provision and political action. In order for the ADAO to promote health citizenship it must recognize the various qualities and alternatives it has to offer individuals affected by anxiety, other anxiety service providers and the public at large. Hence, we come back to one of the primary aims of the thesis, enhancing the ADAO's own recognition and acknowledgement of what it has to offer not just in terms of programs and educational services, but in terms of knowledge production, community and subjectivity.

Chapter Nine - Conclusions

9.1 Chapter outline - why geography?

Invariably the first question I was asked by interviewees asked was: why is a geographer interested in the ADAO, or in anxiety conditions for that matter? The answer as illustrated throughout the thesis is that the experiences of the ADAO and of individuals who are affected by anxiety conditions are intimately spatial on a variety of intersecting scales. One of the aims of the thesis was to provide geographical insights of relevance to the experience of individuals with anxiety conditions and groups that deal with anxiety conditions. The thesis aimed to illustrate the connections between geography and embodied experiences of anxiety, mental health service provision and the negotiation of identity, community and citizenship. Having shown and analyzed why a geographer would be interested by the ADAO, and the relevance geography has for an understanding of the ADAO and of anxiety conditions more broadly, in this conclusion I turn to another aim of the thesis: to contribute to the production of geographical, political, and feminist knowledge and theory. In this conclusion I focus briefly on some of the contributions the thesis has made to the subject of geography. But, before outlining the form and content of the thesis's contributions, I will present an overview of the research project, its development towards this final form and an outline/review of the thesis chapter structure.

9.2 Thesis project overview

From the outset the research has been an interdisciplinary project. Bringing together a wider range of literatures, notably geographical, feminist, sociological, and feminist political literatures reflected an interest in the multifaceted ways of understanding anxiety conditions such as panic and agoraphobia and the organizations that deal with those conditions (the ADAO). It also reflected a desire to challenge the perceived, predominance of bio-medical and psychological - clinical – interpretations, explanations and approaches to anxiety 'disorders' by practitioners and organizations. The use of geographical literature emphasized the centrality of boundaries, spaces and places (both internal and external to the body) within an understanding of anxiety conditions, specifically panic and agoraphobia, and within the context of organizational development. The use of political theory helped to unpack the issue of an embodied subjectivity, which centered on the terms 'healthy citizen' and 'health citizenship'. This presented a significant departure from existing literatures on anxiety conditions, suggestive of the

different ways in which experiences of anxiety conditions and the ADAO can be approached.

Specifically feminist geographical and feminist political theory and methodology was employed because this thesis is concerned to emphasize and uncover voices and experiences that have been marginalized in practice and in the academy. As demonstrated in the literature review, chapter two, drawing from these literatures much emphasis was placed on gaps within the existing literature on anxiety conditions with an emphasis on the first hand, lived experiences and narratives of people with anxiety conditions and members of the ADAO themselves. Because the voices of organizations, voluntary/grassroots/suffer-led/'community based' groups in particular, are absent from clinical and non clinical literatures, this research project was concerned to discover their stories and further explore what these insights have to offer both the organization and academic knowledge production. The stories of those I interviewed simultaneously had an individual and collective dimension that highlighted the centrality of both group/organizational experience and individual experience in the production of selves, subjects and spaces. In making these narratives and issues central to the thesis, my strategy was to prioritize the concerns of sufferers and the ADAO and to allow the research to develop in a responsive manner to their issues and concerns. Hence emerged the question of how to balance the tension between the ADAO maintaining its own direction, creating its own space and networking with other organizations and wider communities in order to receive further public recognition, to expand one's membership, share knowledges, and to gain further perceived 'legitimacy' as an organization. Further, by presenting and situating in-depth inquiries into individual and collective experiences of anxiety conditions, notably panic and agoraphobia, using a wider variety of literatures the thesis emphasized the relevance of those experiences as socially, politically, somatically and spatially mediated. In these ways, it was hoped that a new, more sympathetic and inclusive accounts of anxiety conditions and the ADAO would be allowed to emerge.

These wider literatures were reviewed in chapter two. The literature review provides information about anxiety conditions and agoraphobia and thus lends insight to issues that the ADAO must practically address. However the literature review goes well beyond discussions of anxiety and agoraphobia within the organization to show how anxiety conditions and agoraphobia are of relevance to a wide range of issues pertaining to

geography and subjectivity. The literature review chapter expands on material that helps the reader understand more about issues pertinent to anxiety service provision with specific reference to the importance of geographical work on mental health and 'health care', thus, chapter two focuses on the spatial aspects of service provision and mental health, largely absent within the wider literature on anxiety conditions. The literature review expands on that geographical literature by exploring the connections between anxiety service provision and concepts of subjectivity. In this way the section addresses questions about political and collective responses to anxiety conditions in the form of anxiety service provision. By unpacking and analyzing the issues of care and autonomy the chapter focuses the readers direction towards central themes within the thesis that are instrumental to an understanding of citizenship, mental health, and feminist and geographical scholarship more broadly.

As shown in chapter three, methodologically organizing the thesis was a complex and ongoing process. In the chapter I address some of the complexity of the research process by outlining how I intended to address the project's concerns, explaining the connection between issues central to feminist and feminist geographical methodologies and methods and my approach to the research project. The issue of methodological irony discussed in chapter three, has come not only to be important in thinking about methodological issues, but in thinking about the thesis analysis, and the way in which the thesis has addressed the ADAO's question of where to go next? Methodological irony means that the researcher is positioned in a situation that resists resolution in order to act politically without pretending that resolution has come, to both stay honest and keep moving (Ferguson, 1991:338). The question of what constitutes an effective balance has not been fully resolved in the thesis, and to pretend that such a complex question could be resolved is problematic and not practically possible within the space of the research project. However this does not mean that I do not offer a way of thinking about this tension within the thesis, nor does it mean that the thesis does not provide some insight of relevance to that issue. The focus on health citizenship is both a theoretically informed and strategic one, which offers a different way into the question of organizational 'growth'. An analysis of the way that health citizenship is fostered within the ADAO provides a different way of looking at what the ADAO has to offer its membership and other service providers. The thesis highlights the ways in which the ADAO has created a space of its own that addresses needs not provided for by other organizations and institutions and therefore can potentially inform the direction of anxiety service provision as a whole. It is

important that the ADAO recognize the contributions they make in creating antagonistic and deliberative spaces of difference, because the direction the ADAO has been heading towards moves away from creating spaces in which different experiences of sufferers are addressed. The thesis has shown, as an example of my own 'anxiety' about the direction the ADAO is heading in, that the ADAO is adopting clinical structures and knowledges that serve to homogenize anxiety service provision rather than diversify it. Additionally and more problematically these forms of clinical service provision often fail to acknowledge the daily-lived realities of anxiety conditions, thus further silence many individual and group experiences.

Because of subject of the thesis is the ADAO, it is important to provide detailed information about the group that helps the reader understand more about the organization and its history, as well as help the reader have a clearer understanding of some of my motivations for researching the group, as the ADAO offers a fascinating case study for analysis. This is done throughout the thesis, but is focused on in chapter four where detailed information about important aspects of the organizations history, structure, mandate, services, programs and background information on the relationship between the ADAO and other service providers within the city and country. In so doing chapter four involves a critique and analysis of the power relations involved within the ADAO, and between the ADAO and other anxiety service providers that helps the reader understand why the tension between adopting other voices and celebrating one's own voice is such a crucial and central issue. This chapter provides information that helps to construct new and critical questions about knowledge practices and power relations that are constitutive of the identities and communities that have shaped the ADAO in more precise and informed ways.

The next four chapters provide the substantive material of the thesis and use interview material as well as collected data from the ADAO and other service providers to expand on a variety of themes, theoretical propositions and highlight the importance of health citizenship in the context of creating spaces in which difference are possible. Spaces that directly contribute back to the productive development of sufferer's identities, subjectivities and communities. Each chapter is its own story, connected together through themes such as health citizenship. Within chapters five through eight the thesis argues for the development of 'health citizenship' as opposed to a model of the normative 'healthy citizen' upon which the clinic and health care practice is based. The substantive chapters

move back and forth between models of health citizenship and the healthy citizen arguing that the ADAO relies on both forms of subjectivity. The thesis has examined the tensions involved in negotiating the place of healthy citizens and health citizenship within the ADAO. Both the healthy citizen and health citizenship are important for the ADAO, as the ADAO must address that there are sufferers who want, and need, to be a part of an established and hegemonic clinical care culture, as well as, those who do not accept or fit within those structures and need alternative places from which to get assistance and inspiration. The healthy citizen-subject is an abstract ideal created and maintained by processes of governmentality, expert knowledges and a self-care ethic. The healthy citizen is able through detached objectivity, self-discipline and a bounded, 'independent', sense of self to become an effective, productive member of society. Health citizenship highlights the needs and lived experiences of individuals with anxiety conditions and incorporates those experiences into a model of citizenship and subjectivity rather than using those experiences as something to strive against, thereby ignoring many of the realities and problems faced by those with anxiety conditions. Rather than negating one's own experience of ill health in the pursuit of an ideal of an 'able' sickness free body and subjectivity, the experience of ill health becomes a constituent part of citizenship as opposed to its antithesis. Thus, the thesis argues that through the development of health citizenship the ADAO potentially offers a better model of subjectivity and community that help to create alternative forms and geographies of active citizenship and radical democracy.

In chapters five, 'body', and six, 'mind' I elaborate on aspects of the healthy citizen, and how the healthy citizen is linked to the production of specific beliefs about the body and the self. In these two chapters I show how the healthy citizen is predicated on the construction of a docile body that is inscribed by normative and hegemonic forms of clinical care. In these two chapters the issue of lack of self-trust about the body and the self are instrumental in understanding how the healthy citizen is formed. Additionally, chapter five posed a question about whether an examination of the body can help to achieve more emancipatory social and political relations in addressing issues of marginalization and social justice (Longhurst, 2000:5). The thesis has shown throughout that health citizenship is concerned with body politics. In a model of health citizenship embodied subject positions, the spaces of the body, and the relationship of the body to wider geographies are central to exposing forms of marginalization and creating more deliberative, anagonistic and antagonistic forms of social justice. Chapter five, 'body',

focuses on how surveillance and visibility of the body helps to create a docile body, which must be seen in specific ways through specific lenses in order to be understood. The body is made comprehensible through the knowledge of clinical practices, which are then internalized and adopted by sufferers as their own. I explore how the need for the body to be seen creates problems for individuals and organizations that deal with anxiety conditions.

Chapter six, 'mind', focuses on how forms of knowledge production help to create a docile body. The privileging of expert or professional forms of knowledge helps to establish who can make claims about the self. I explore how the ADAO has adopted the importance of expertise in order to be more accepted within the mental health service sector and to be seen to be a more legitimate 'clinically based' organization. These two chapters however, also point to the ways that the healthy citizen is adopted and resisted by the ADAO in subtle, yet important ways. In this way the thesis suggests that there is always the possibility of resistance to the healthy citizen even within those discourses themselves.

The next two chapters explore how the ADAO works towards a version of health citizenship that focuses on spaces where the possibilities of difference and diversity are actualized. The chapters highlight that the ADAO serves an important function within the mental health community by providing alternative approaches and structures to sufferers, which may in fact be more democratic and equitable. In this way the thesis posits that the ADAO offers a better model of subjectivity, identity and community than do many other service providers. Thus the ADAO is an important organization whose usefulness needs to be acknowledged by the mental health community more broadly and the organization itself. Both, but especially the ADAO, need to recognize and celebrate what the ADAO has to offer a wider public that is different from what already exists within the mental health service sector. Chapter seven, 'heart', focuses on what makes the ADAO different from other service providers, stemming largely from the fact that it is a consumer led initiative based in first hand knowledge of anxiety conditions and lay expertise. In this chapter I explore an aspect of its uniqueness - its focus on relational autonomy. In other words the importance the ADAO places on relations of interdependence and interconnectedness within relationships that are often mutual and non-rigid help establish the ADAO as a different kind of service provider, with different things to offer sufferers and the wider public. In this way health citizenship is linked to reclaiming self-trust and challenging the idealization of independence upon which the healthy citizen is predicated.

Chapter eight, 'breath', focuses on how issues developed in the heart chapter are translated into alternative material spaces of difference. The breath chapter is specifically about elaborating aspects of health citizenship through the example of the volunteer companion program, and linking health citizenship to ideas about democracy and community development. These two chapters specifically used concepts and themes that are not conventionally thought of in the context of anxiety service provision in order to challenge the criteria by which health service providers are judged. The concepts of relational autonomy and health citizenship were chosen because they exist as discourses that remain disconnected from work within, and by, the ADAO and yet are intimately connected to the work of the ADAO and to understanding or improving the quality of people's lives more generally.

In summation, the ADAO is an organization that has the potential to affect individuals' lives, the life of the community and the world of politics. The ADAO is engaged in a form of politics that is different and antagonistic in many ways from its context of service provision. This needs to be acknowledged, celebrated, or at least worked with in productive ways. In other words the thesis argues that the ADAO is an important organization that serves as a model of democratic possibility and of change. This thesis aimed to show that anxiety conditions, and the organizations that address issues of anxiety, provide important, instructive lessons and knowledges about the content and contexts of western societies. Experiences of anxiety do matter and need to be counted, not just individual experiences but collective and organizational experiences as well.

9.3 Thinking about citizenship through the ADAO case study

Within the thesis I focused upon two interconnected yet fundamentally different models of citizenship - "the healthy citizen" and "health citizenship". The healthy citizen involves the pursuit of an ideal 'able', sickness free body and subjectivity. This is central to both the clinical care system that often bifurcates the experience of ill health in favor of outcomes. The healthy citizen refers to a model of citizenship in which individuals strive towards goals and versions of personhood that are given to them, which are then reworked in directed, specific but multiple ways. The healthy citizen is based on ideals and ideas that have helped structure various dualisms, such as mind/body, able/disabled, man/woman. It is a model of citizenship that is not concerned with a complex variety of embodied experiences, but rather that seeks to bring people together towards a particular

version of embodiment associated with productivity and health that we must comply with in order to be recognized as citizens. Alternatively, within a model of health citizenship the experience of ill health becomes a constituent part of citizenship as opposed to its antithesis. Health citizenship actively fosters the needs and lived experiences of individuals with anxiety conditions and incorporates those experiences into a model of citizenship and subjectivity rather than using those experiences as something to strive against.

I have demonstrated how both these models are demonstrated in practice by the ADAO. On the one hand the move towards clinical approaches and models that have largely been developed by experts and professionals *for sufferers* is an example of the model of the healthy citizen, while as the incorporation of aspects of anxiety health based on the lived experiences of sufferer's themselves *by sufferers*. For example, a focus on alternative nutritional practices and the need for volunteer companion-helpers is an example of health citizenship in action, while the continued reliance and discussion of bio-medical protocols and the need to include more expert professionals is an example of the ADAO's need to incorporate a model of the healthy citizen. I have also demonstrated that these differing models of personhood are expressed through different geographical patterns and environments. The healthy citizen, within the context of anxiety service provision, tends to be located as forms of governance within institutions, institutional practices connected to wider health and public health policies and organizational networks that have been well established. However, as noted within the thesis by authors such as Lupton and Petersen, the concept of the healthy citizen is one that has been readily adopted as a form of the new public health or within contemporary public health practices. As such the healthy citizen is located in a wide array of places and persons extending from and beyond clinical institutions. The healthy citizen is far more likely to look for assistance in dominant clinical landscapes and institutional geographies, while as a model of health citizenship tends to be diffusely located outside of or in opposition to the spaces of clinical expertise and power. This has an affect on the creation of power relations and feelings of empowerment. Health citizenship and practices of health citizenship can be found within various institutional or clinical settings, its geography tends to be far more varied, located in different complex socio-spatial settings often outside of an institutional framework. The geographies of the body are also affected by differing versions of citizenship. How we come to understand our bodies is contingent on what embodied

experiences matter and are counted. In this sense differing visions of citizenship have a significant impact of issues of self-empowerment and power relations with others.

Both models can be empowering and disempowering. Both actively foster different types of community and spaces of community. However as I have argued throughout the thesis for those individuals with anxiety who never quite research the 'ideal' of a sickness free body, the healthy citizen can be a disempowering and disheartening ideal, while health citizenship (which can be equally depressing) can be directed to enhancing those individual's sense of personhood and subjectivity through aspects of sociability and community development. Within the thesis I have explored how health citizenship can involve looking for alternative radical democratic spaces of citizenship connected to processes of community development and organization. The example of the volunteer companion program that take into account the lived daily needs and realities of agoraphobic sufferers is an example of how health citizenship is connected to processes of empowerment, mobility and feelings of belonging which further fosters processes of community and subjectivity. Through this discussion of health citizenship and the volunteer companion program I have also explored how models of health citizenship means looking for different expressions of citizenship beyond the public-private divide. Health citizenship is a process where people are positioned in complex ways that may help to resist or subvert existing meanings and spaces of the political, extending meanings of the political beyond that of the institutions of the 'clinic' or 'state'.

The thesis demonstrates that the tension the ADAO has between balancing its desire to create a space for itself alongside its desire to network with other service providers is a reflection of the tension between health citizenship and the healthy citizen. Additionally the ADAO's move back and forth between these models is a reflection of the diversity of viewpoints in the wider community of sufferers to anxiety service provision. Having the ideal vision of the healthy citizen can be very useful for some, and very destructive for others. Though I have presented these models of subjectivity in opposition to one another intentionally, practically these models are situated in a continuum alongside each other at different times and in different contexts. This does not mean however that these models work with similar understandings of embodiment and subjectivity, rather that they are not mutually exclusive. In further research and study drawing out that continuum and the slippage between these models would be useful in the context of further thinking about

the issues and tensions raised within the thesis. This lack has been a primary limitation of the study.

The analysis of citizenship is limited within the context of the thesis largely due to my desire to present the viewpoints and opinions of an organization that is struggling within a landscape of anxiety service provision. In this way, and for this reason I have unfairly polarized health citizenship and the healthy citizen. This may not be so much the product of studying an individual organization or case study, but recognition of how my embeddedness within the ADAO and empathy for its needs desires and causes affected the analysis of the thesis. Ultimately the research has been directed by my empathy for the problems I observed during the research process, motivated by my fear of the direction that the ADAO seems to be heading. The focus on health citizenship is directly connected to my anxiety that the ADAO is moving more towards models of the healthy citizen, away from constructing spaces of difference, thus reducing the potential number of alternatives for sufferers within the mental service sector.

The trend towards the healthy citizen is found not only within the mental health sector but also, within the third or voluntary 'health' sector more widely. From mental health groups to women's shelters more organizations are being coerced and forced to adopt practices of the clinic that highlight the importance of professional clinical expertise and technologies of visualizing and surveying the body over other knowledge practices and forms of lay and non clinical expertise. The move towards adopting the healthy citizen and practices of the clinic, illustrated within the 'body' and 'mind' chapters, is such a pervasive process that it has almost become commonsensical, the direction that organizations must take to stay alive. This, for me, is problematic and needs to be actively questioned for its potential to affect people's lives. The thesis illustrates, using the case study of the ADAO, that the path towards the healthy citizen is fraught with complications for individuals and groups.

Part of the problem in adopting the healthy citizen is that organizations such as the ADAO are not positioned to recognize the important contributions they make to the wider societies they are a part of. This means that those groups may not value what they have to offer, and thus are more likely to adopt other methods, ideas or directions that make the group more profitable or recognizable by more dominant service providers. In response to this, the thesis suggests that the ADAO has a considerable amount to offer. The thesis

specifically used concepts and themes that are not conventionally thought of in the context of anxiety service provision in order to challenge the criteria by which health service providers are judged. The concepts of relational autonomy and health citizenship were chosen because they exist as discourses that remain disconnected from work within, and by, the ADAO and yet are intimately connected to the work of the ADAO and to understanding or improving the quality of people's lives more generally. The ADAO is an organization that has the potential to affect individuals' lives, the life of the community and the world of politics. Ultimately while the research has been limited by a more polarized analysis of models of citizenship and presents a partial viewpoint of the context of anxiety service provision, the thesis provides a point of departure from which to develop future questions, more comparative analytic frameworks and explore different forms of discourse.

9.4 Thesis contributions, and future questions.

In this section I touch on some of the contributions the thesis makes to academic research in the discipline of human geography. This is reflected in the implications of the thesis findings for wider academic audiences. I focus on what health, and mental health geographers can take from the thesis and how those findings help reshape current agendas within health geography? I conclude the thesis with a discussion of what future questions arise from the research project.

In the introduction of the thesis I offered three general aims that the thesis has worked towards. First, to highlight the importance and relevance that anxiety organizations, and the experiences of its membership, have for further study. Second, to provide geographical insights of relevance to the experience of individuals with anxiety conditions and groups that deal with anxiety conditions. And third, to contribute to, and expand on, geographical, feminist and political theory by illustrating the connections between geography, embodied experiences of anxiety, mental health service provision and the negotiation of identity, community and citizenship. These aims have been met in different ways within the thesis project.

The thesis has introduced the reader to importance of the experiences of sufferer-led anxiety organizations for geographical study, while expanding on a growing literature within geography on the anxiety condition agoraphobia. In so doing the thesis has

explored also the intersection between community, institution and identity in ways that highlight the important of organizations in mediating individual and collective identity, a sense of self, and a sense of place. It is important to further study voluntary groups and community based organizations that address mental health issues, as they enhance an understanding of the geographies and processes of health for individuals and groups.

The thesis has bridged themes and issues in diverse areas of interdisciplinary scholarship, as well as bringing together issues within human geography, i.e. feminist geography, mental health geography, in innovative ways that suggest possibilities for further research. This is not new to human geographers who draw increasingly on different areas of geography and “other disciplinary fields to elucidate the complex connections between the human individual, the social collective and various ‘spatialities of the self’” (Parr, 1999b: 673).

The thesis also discusses issues central to feminist political theory using geographical insights, which contribute to the production of both geographical, feminist and political knowledges and theory. The research has expanded on some subjects discussed within human geography such as care, community and citizenship. The thesis has shown that some concepts in feminist political theory, such as autonomy and relational autonomy, have not been directly or well explored within human geography. These concepts are both useful in thinking about concepts and questions within mental health geography in particular, thus further exploration of autonomy is needed within the discipline.

Additionally, there are other more specific contributions that the thesis has made to geographical knowledge production, methodology and theory.

First, the thesis has introduced a number of specific concepts that are relevant and potentially useful for other forms of geographical inquiry. First, methodological irony is methodologically useful in thinking about different aspects of the production of geographical research and that is of relevance to further feminist geographical research and thinking about issues of the ‘field’. Second, spatial recognition skills highlight the importance of understanding space and place as constitutive of self and subject. This has implications for the development of feminist political theory around the issue of autonomy, and the insights geographical theory provides for a feminist politics. Third and most notably, the issue of the healthy citizen and health citizenship. The concept of health

citizenship has the potential to contribute to insights within geographical literatures in ways that connect issues of political relevance to geographical analysis. Health citizenship is based on a pivotal issue found throughout human geography related to how the conceptualization and material construction of bodies make a difference to our experience of place. The thesis has explored the variety of ways that bodies are materialized, inscribed and (re) located in place and as space (Duncan, 1996b; Pile and Thrift, 1995). A discussion of health citizenship highlights how our bodies help us to 'map' people's geographies, communities and identities throughout the life course. These issues are all central to human geography. Health citizenship brings to the fore the issue of who counts (whose body counts) as the bearer of knowledge and whose experiences and geographies are privileged or marginalized (Chouinard and Grant, 1995; Dyck, 1998; Moss and Dyck, 1996; 1999b). Health citizenship is concerned to explore the various interstices through which diversity and difference can be explored. Thus health citizenship is of particular interest for feminist geographers who are concerned to explore the stories of those who remain unheard. The concept of health citizenship needs to be expanded on further using information and theory from other areas of geography, such as political geography and cultural geography in addition to feminist and health geography to further expand on the varied meanings of health citizenship.

Second, the thesis makes connections between geographies of the body, geographies of mental health and geographies of fear in innovative ways. These connections highlight the centrality of embodiment within the research process, hence the focus on health citizenship as an embodied politics. The substantive chapters of the thesis begin by drawing on and contributing to geographical theory on the body. Focusing on the body as a lived geography, a medium through which to understand spatial relationships and the nature of place. Bodies become sites of political contestation that act as a critique of the ideal of universality, detached objectivity and rationality central to a model of the healthy citizen.

The thesis has not only investigated the body's internal spaces, but the way in which those internal geographies are connected to imagined and material environments. In this way the thesis has contributed to an area of mental health geography that requires further discussion. The thesis focuses not only on the shifting boundaries between interior and exterior explored in relation to the creation of environments within and outside of the

body itself, but the relationship between, fantasy, delusion, imagination and memory which brings a new dimension to thinking about the body, identity and subjectivity. This can translate into concrete and imaginative geographies that feed directly into a landscape of social exclusion, marginalized by others or self marginalized, as is the case with many agoraphobic individuals.

Criticisms have been made of the way in which corporeality has been approached in mental health geographies. On the one hand, the body in medical geographies “simply becomes the site invaded by disease with a specific etiology” (Hall, 2000: 21). And on the other medical/health geographies have focused so extensively on representations of the body the spatialities and implications of the physical presence of the body are neglected (Parr, 1998a:28). This thesis has confronted this concern directly intertwining clinical and non-clinical representations of anxiety conditions to the lived and somatic experiences of those with anxiety conditions such as panic and agoraphobia, and how that is further negotiated by groups that deal with anxiety conditions. In so doing the thesis has paid critical attention to the spaces of clinical practice in relationship to the body, clinic, and community in ways that decenter (Dyck, 1998) but do not disregard the clinical, which is considered central for the study of health geography (Hall, 2000; Parr, 1999a; 2000; Philo, 2000). Additionally the thesis has posited that bodies are dynamic and complex spaces of individual and collective resistance whereby biomedical inscription interweaves with bodily and social experiences in complex ways (Dyck, 1998, Chouinard, 1999). Thus, as shown through the healthy citizen and health citizenship that the discursive formation of the healthy and unhealthy body is a complex signification process whereby the body becomes socially, economically, and politically legitimized in culturally intelligible ways (Moss and Dyck, 1999a).

The analysis of the body in chapter five taken together with chapter six of the thesis expands the geographical literature on the body by connecting geographies of embodiment, to work on the geographies of fear and the geographies of mental health. Chapter five highlights how the stigma of the mental affects processes of identity and subjectivity focusing on the body and self as an imagined geography. The stigma of the mental also affects geographies outside of the body, both imagined and concrete. The stigmatization of mental illness comes to affect how people understand themselves, their bodies, others around them, and the worlds in which they live. This chapter focuses on how the stigma of the mental is associated with the places of institutionalization- “a

process of tertiary spatialization" (Foucault, 1976), rather than on the specific imagined geographies of panic sufferers themselves. The thesis has explored how landscapes of fear are interconnected to landscapes of care based in forms of governmentality.

"Landscapes of care" involve an examination of how anxiety service provision is spatialized and how meanings of care are defined, created and located within and by those geographies (Gleeson and Kearns, 2001). In this way geographies of knowledge production are connected to patterns of anxiety service provision and community organization.

And third, a central concern for geographers involves the issue of boundaries that is addressed within the thesis. The thesis as a whole is concerned with the issue of boundaries, whether those boundaries are material and embodied or metaphoric and discursive. Boundaries between what is internal and external to the body, between self and other, between self and subject, between individuals and groups, between researcher and researched, boundaries between groups, boundaries between theory and practice, and boundaries within disciplinary knowledge production. These boundaries can be divisive; they can be enabling; they can form a 'crisis'; they can be blurred, interdependent and transformative of the other; and boundaries can point to the limits and possibilities of knowledge production and political action. Thinking about boundaries is central to a geographical project concerned with spaces in which difference is possible and actively worked with.

While the titles for chapters five and six, 'body' and 'mind', refer to a legacy of Cartesian dualisms which have separated body and mind in deeply problematic ways that need to be challenged, the chapter titles for chapters seven and eight 'heart and 'breath' are metaphoric for intersectional and interpersonal boundaries between self and other, and the interconnectedness of boundaries between self, subject and environment respectively. In chapter five 'body', the connection between self and space is explored with a particular focus on embodiment, bodily boundaries and geographies of the body. In chapter six 'mind' the connection between self and subject is explored through an analysis of competing boundaries of anxiety knowledge production within landscapes of care. Taken together these two chapters illustrate how the negotiation of embodied boundaries, of what is inside and outside of the body, the somatic and the spatial, profoundly affect the boundaries of self and other and self and subject.

Chapter seven, 'heart', explores how boundaries between self and other are relational, thereby implying that the boundaries of networking with others is central to the process of creating a space of one's own. The chapter focuses primarily on how the ADAO's understanding of relational boundaries contributes to the effectiveness and usefulness of its programs, and what the organization has to offer that is unique within the context of anxiety service provision. The chapter celebrated the ADAO's capacity for creating interpersonal relational spaces in which interchange contributes to self-trust and well-being. Chapter eight, 'breath', extends the discussion of relational boundaries to include a discussion around community and the public/private divide, challenging the traditional boundaries between public and private spaces and the public and private sphere. The ADAO, through its volunteer companion program extends and complicates the boundaries between public and private thereby offering new ways of exploring the boundaries of community and the construction of citizenship.

The issue of boundaries could also be framed in terms of attachment and detachment. Chapters five, 'body', and six, 'mind', focus on processes of detachment. For example, the "boundary crisis" of a panic attack and resulting agoraphobic avoidance behaviors that further separate the individual from the spaces in which they live and other people, or the process of othering the self involved in the stigmatization of mental illness that further detach those individuals from a positive subjectivity and from engaging with others to form a sense of community. In contrast chapters seven, 'heart', and eight, 'breath', focus on processes of attachment and reattachment. These processes of attachment relate the self to other in positive, enabling ways through a recognition of the interconnectedness of space, self, identity and community.

The thesis may have productively contributed to areas of knowledge production but the thesis leaves open many areas that are in need of further discussion and investigation. There has been an increase within the geographical literature on anxiety conditions such as agoraphobia; however, there is still a long way to go, and many more issues to address. This thesis has not covered all anxiety conditions, such as post traumatic stress disorder or obsessive compulsive disorder, which offer new directions for study and literature. Issues such as race, immigration status, ethnicity and socio-economic factors such as poverty, education and class could enrich an analysis of anxiety conditions and the organizations that address these issues. Additionally, while this thesis reflected interviewee's discussions and perceptions of the context of anxiety service provision,

more work is needed that presents a more nuanced and complicated analysis of the relationship between non clinical, clinical, self help and alternative practices around anxiety conditions.

Finally, it is hoped that the thesis will contribute to increased interest within health geography about a body politics. The thesis research points to an opportunity to expand on the politics of mental health geography within the discipline. The issue of health citizenship needs to be more fully explored within different contexts and using different theoretical frames of references such as risk theory, disability studies and public health management; using different political theorists, for example Habermas, Lefebvre and Arendt, whose work is directly connected to geographical issues; and using the work of different geographers situated in different sub-disciplines. Additionally while the thesis did not work with much political or cultural geographical work, drawing together political and cultural geography with work within health geography and feminist geography would be useful.

Appendix I - Letter of Introduction

Date:

Ruth Bankey

Ph.D. Student, University of Edinburgh

Email: rba@geo.ed.ac.uk

Web site: www.geo.ed.ac.uk/~rba/

Tel: (613) 236 3990

Dear Participant,

My name is Ruth Bankey, I am a researcher and Ph.D. student at the University of Edinburgh in the department of geography. I have been researching issues pertaining to agoraphobia and panic disorder for the past three years. I first became aware of the Anxiety Disorders Association of Ontario in 1997, which at that time was known as the Agoraphobia Peer Support Network, when I began my Master's research on agoraphobia at Carleton University, Ottawa. Since that time I have seen the ADAO expand its program base, contacts and membership. I am very interested in the growth of the ADAO as an organization because, in spite of its success, many other panic, anxiety and agoraphobia community groups and organizations across Canada have not had similar successes.

I am interested in talking to persons who have been consulted or worked with the ADAO since its inception in order to better understand why the ADAO has developed into the organization it is today. I think that this research will not only be beneficial to the ADAO itself and its membership, in that it will provide a thorough record and analysis of its history, but I believe that this research will help other community groups and associations in better understanding what makes for an effective organization.

I hope that you will agree to participate in this study, because it is important and ground breaking research. I am asking you to participate in an interview, the time and date to be set up at your convenience, and perhaps a follow up interview at a later date. If you agree to participate in this research, I ask you to sign an informed consent form which outlines your rights, provides more details of this study and lets you know that the information you provide will be treated confidentially and respectfully.

If you have any questions or concerns please feel free to contact me at the addresses or numbers above. If you would like more information on my research I have a research web site at www.geo.ed.ac.uk/~rba/. I appreciate your taking the time to consider participating in this study.

Sincerely,

Ruth Bankey

Appendix II - Informed Consent Form

I have spoken with Ruth Bankey concerning her research on panic and agoraphobia communities and have read the letter of introduction informing me of the research and its purposes. I, _____ consent to participate in this doctoral research project conducted by Ruth Bankey in order to express my views on the subject.

I understand that my participation in the project will include the following activities and terms (This is a flexible document and can be added to or modified at my _____ request):

1) I understand that I have a right to withdraw from the research process at any time regardless of the reason without recrimination. I have a right to refuse to answer any question and have a right to request the erasure of any record with which I am uncomfortable for any reason.

2) I understand that the research process may involve a number of interviews and that the time and place of the interview will be mutually agreed upon. The interviews will be taped and transcribed and all transcripts and audio recordings will remain confidential and placed in a secure locked location.

3) I understand that (please choose one of the options)

(A) Personal names or any other information which would serve to identify myself as an informant will not be included in this thesis.

(B) Personal names or other information which would serve to identify myself as an informant can be included in this thesis.

4) I understand that I can receive and review a written transcript of the interviews and that I can suggest modifications for accuracy or to add new information.

5) I understand that the information from the interviews will be used in the construction of a thesis document, which may be used in further research and/or published. I also understand that I will be informed about the research process as well as the findings progress of the research thesis process. I understand that a summary of the research findings will be made available to me if I request it.

Participant: _____

Researcher: _____

Date: _____

Appendix III - Interview Schedule - (examples of questions)

1) Background -professional/occupational information and positions

- What paid or unpaid work do you do?
- What is your role? As a practitioner why do people come to you?
- How long have you been/worked in the Ottawa area?
- Have you worked with other anxiety/panic/agoraphobia organizations, individuals elsewhere?

2) What is panic and agoraphobia, viewpoints of panic and agoraphobia and how it should be addressed

- How do you define Panic and agoraphobia
- Do you make a distinction between Panic and agoraphobia
- What is your sense of what happens to people with panic, during a panic attack, during a period of agoraphobia avoidance?
- Do they seek help? From whom?
- How do you think panic and agoraphobia is understood or seen by others, by the 'public'?
- How do other people react to (your) panic and agoraphobia?
- Can you think of any media representations of panic and agoraphobia?
- Do you think panic and agoraphobia is taken seriously compared to other health conditions?

3) Personal background information on why they work with persons with anxiety conditions or joined/volunteered for the ADAO

- Why did you become interested in/involved in working with persons with anxiety conditions?
- Why did you become interested in/involved in working with the ADAO?
- How has your own anxiety condition affected the ADAO?

4) What is there personal history in relation to the ADAO, what are their roles within the ADAO? What have they done for and with the ADAO? Who have they worked with? Interaction with other members

- Could you describe your personal experiences and history, starting from when you first joined the ADAO till today?
- What was your first impression of the ADAO, its members, has that changed? Why? In what way?
- How would you describe what panic and agoraphobia are based on your experience with the ADAO?
- What have you enjoyed most or least about working with the ADAO? Any examples to help elaborate?

5) Questions about ADAO's organization, history, viewpoints, challenges, future directions

- Could you describe to me, based on your time at the ADAO the structure of the ADAO, then and now?
- Could you provide me with a time line and history of the ADAO itself?

- What are some characteristics that describe the ADAO when you first joined, characteristics that stand out in your mind, both positive and negative?
- What were the implications of those characteristics for the organization?
- Future directions, suggestions for the ADAO?

6) Anxiety, panic, agoraphobia and service provision

- What barriers, problems, advantages exist for providing services for those with anxiety conditions, panic, agoraphobia?
- What services exist in Ottawa?
- What services does the ADAO provide?
- How do you think services should be, could best be, provided for persons with anxiety conditions? Internet? Outreach programs? Educational Programs?
- Are there differing opinions within the city about service provision?
- To what extent is service provision dependent on funding?
- What is the ADAO's history of funding, what is funding like within Ottawa for anxiety conditions?

7) Anxiety conditions, community and the Ottawa area

- What other anxiety/panic/agoraphobia communities exist in the Ottawa area that you know of?
- How are these linked, related, connected to the ADAO? The health care system?

8) Anxiety conditions and the Internet

- Have you ever used the Internet for PDA research, in your practice or information?
- How has the ADAO used the Internet? Positive negative experiences and aspects?
- How has the Internet affected the organization and effectiveness of the ADAO?

9) Anxiety, Panic and agoraphobia and gender issues

- I've noticed that most of the staff, volunteers and consultants are women, do you think this has affected the way the ADAO is run, the dynamics of the organization and its effectiveness? Why?
- I've also noticed that most of the people who join and use the ADAO are women, how has this affected the way in which the ADAO has developed and been organized?
- Generally speaking, do you think gender is a factor in the success or running of the ADAO? Has it been discussed?
- Have you thought about why the ADAO is mostly women? Has it affected its programs?
- Often panic and agoraphobia are described as a female disorder, given your experience with the ADAO what do you think about this statement?

Appendix IV – Revised and Additional Interview Schedule of Questions

Questions:

- 1) How did you come to be involved with the ADAO? What were your first impressions of the ADAO and/or members of the ADAO? Have those first impressions changed? How and why?
- 2) What has been your involvement (different roles) with the ADAO and what have those various roles or positions involved?
- 3) What did you enjoy most and least about working with the ADAO?
- 4) What are some of the ADAO's positive and negative characteristics, its strengths and weaknesses?
- 5) Given your previous work in Ottawa what did you/ do you see as the role of the ADAO within the city relative to other health service providers (ROH, CMHA, private clinics, universities) and the general public?
- 6) What future directions, or roles would you like the ADAO take? Or perhaps are afraid may happen?
- 7) The ADAO uses the term panic condition as opposed to the DSM's panic disorder. Language is an important issue within mental health that is central to the construction of identity, the professionalization of knowledge, etc.. How would you discuss issues of language in your experience of working in the area of anxiety, panic and agoraphobia.
- 8) In my interviews so far the word 'heart' has come up time and again both as an important characteristic of panic (heart palpitations, heart attack) and as a way of distinguishing between different kinds of services within the city (they have a lot of heart, she really puts her heart into it). In critically thinking about clinical and non-clinical services for persons with anxiety, panic and agoraphobia how would you use the term 'heart', in the context of Ottawa? **Same question for body, mind and breath**
- 9) How are various services within Ottawa perceived? Are there 'tensions', differences and politics between different types of services- or perhaps you have a very different image of anxiety, panic and agoraphobia services in Ottawa).
- 10) Often ailments such as panic are perceived of as a 'private' individual problem by a wider public - its 'your' problem. What do you think about this statement? Is it a private concern, a public concern? How do various services in Ottawa (ADAO, ROH, etc...) take this kind of sentiment into account in its programs and functioning?
- 11) Do you think panic, anxiety and agoraphobia are taken seriously (especially in comparison to other conditions) by the public? Why/ why not)? Why isn't there a more public discourse on these issues? Have you seen anyone or any organization try to address this concern? What did they do?

Appendix IV - Heart Codes

Each word or code is a section that contains examples and excerpts from the transcripts or from quantitative data provided by the ADAO. They should be read as headings and subheadings. Due to reasons of confidentiality and space within the thesis text- those quotes are not included. Some codes are repetitive, this suggests my interest in the material.

Step 1 - Heart - Examples in the text

- ❖ Listen from your heart
- ❖ Heartfulness
- ❖ Heart attack
- ❖ Open hearted
- ❖ Heart in the right place
- ❖ Good hearted
- ❖ Heart and soul
- ❖ It's in her heart
- ❖ Heart of the whole thing
- ❖ How much heart is going into that area
- ❖ Have a heart
- ❖ Bleeding hearts
- ❖ My heart pounds
- ❖ Heart-stethoscope to listen to heart
- ❖ Heart disease
- ❖ Heart rate
- ❖ Put my heart in 100%
- ❖ A great deal of heart

Step 2 - General issues that arise in those examples. Themes surrounding those examples- new coding words or phrases- use codes throughout text

- Care
- Love
- Emotion
- Compassion
- Empathy
- Openness
- In/dependence
- Interdependence
- Physical sensational of panic
- Safety
- Community
- Energy
- Heath issues
- Professionalism
- Friendship
- Control
- Trust
- Power
- Authority
- Passion

- Drive
- Motivations
- The body
- Status
- Help/helpers/helping
- Volunteering/volunteers
- Connecting
- Networking
- Work
- Private/public

Step 3 – Highlighting Issues - go beyond individual words to develop discrete themes

- 1) Heart and the center of things- issues of centrality
- 2) Heart celebrating difference
- 3) Nurturing the group and the individual
- 4) Heart notions of self
- 5) Connecting community identity with self identity
- 6) Characterizing the organization with heart
- 7) Expressing processes of dehumanization
- 8) Misperceptions of the body
- 9) Specific examples
 - Heartfulness
 - Spirituality- mind body place interconnections

Step 4 – Selective Codes – development of more specific issues

- 1) The physical experience of panic
 - Reminder of the presence of the body
 - Separation of body-other-space
 - Loss of control over body
 - Individual/private sensations
 - Legitimacy of ailment
 - Labeling/rootness of biomedical
- 2) Reference of the emotional
 - Defining individuals
 - Defining communities
 - Defining organizations
 - Passion/drive
 - Compassion
 - Empathy
 - Friendship/family

- 3) Differentiating between
 - Professional/lay
 - Personal/ institutional
 - Clinical/. Non-clinical
 - ADAO/ROH
- 4) Heart relationships between self and other
 - Care and compassion
 - Trust and friendship
- 5) Heart Discourse and Knowledge Production
 - Openness, receptiveness
 - Multiplicity, diversity of ideas
- 6) Heart- charity, voluntary, grassroots
 - Qualities of voluntary, charitable, grassroots organization
 - Nature of paid/unpaid work
 - Personal investment in-group
- 7) Characterizing the organization with one person
 - Issues of risk
 - Issues of safety
 - Issues of transition
- 8) Organizational management- issues of trust
 - Need to foster trust
 - Centrality of trust in programs, services
 - Motivation of staff, volunteers, board
 - Trust within the system
 - Clinical trust/ non-clinical trust
- 9) Qualities of organizational development
 - Transition from one person's baby or idea to group and collective status and recognition
 - Qualities of volunteers
 - Qualities of staff
 - What people bring to the group?
 - Leadership
- 10) Differentiating types of knowledge
 - Around caring practices
 - Institutional/voluntary
 - Clinical /non clinical
 - Lay/professional
 - Holistic/scientific directed
 - Human centered/goal centered
- 11) Processes of dehumanization
 - Forms of negation

- Treating person or problem
- 12) Creating respectful relationships
 - Heart precursor for effective group politics
 - Amongst staff
 - Amongst board
 - Amongst volunteers
 - Between health care services and individuals
 - Between heart care providers themselves
 - ADAO and membership
 - 13) Obstacles
 - Too caring/attached
 - Vulnerability
 - Business like /professionalism
 - Issues of attachment/detachment
 - How professionals should act
 - Creation of appearances
 - 14) Centrality of emotions on board
 - Sympathy/empathy
 - Running the board
 - Forms of authority, power and hierarchy
 - 15) Relationship between individual and group
 - Ethical issues around exposure
 - Safety
 - Issues of growth
 - Autopathographies
 - 16) Creation of safe spaces
 - Response to panic
 - Reflections of divisions in service provision
 - 17) Make space for the organization
 - Its own space
 - Having a space

Step 5 - Connecting Codes with Theory

- 1) Heart as an expression of how people are relational
 - Simultaneously emotional, social, political and embodied
- 2) Heart as metaphoric for the relational self
 - Self characterized by attachment
 - Fosters personal drive and passion
 - Autonomy through example
 - Autonomy through instruction
- 3) Developing self trust

- Self-knowledge through ethic of trust
 - Ethic of care/justice
 - Ethic of informal others/formal others
 - Negotiating friendship
- 4) Independence/dependence/interdependence
- The relational
 - Self/other
 - Self/subject- intersubjectivity
 - Autonomy and other forms of subjectivity
- 5) Heart- passion and autonomy competency
- Identity and community
 - Intersectionality
 - Organizational issues
 - Passion not as individualistic but as connective drives and motivates people to do things and to move towards others
 - Issues of self-trust
 - Positionality
- 6) Heart and the authentic self

Bibliography/References

AGORAPHOBIA AND PANIC VOLUNTEER ASSOCIATION (1997a) APVA
newsletter first edition

AGORAPHOBIA AND PANIC VOLUNTEER ASSOCIATION (1997b) APVA
newsletter second edition

AGORAPHOBIA AND PANIC VOLUNTEER ASSOCIATION (1998a) APVA
newsletter third edition

AGORAPHOBIA AND PANIC VOLUNTEER ASSOCIATION (1998b) APVA
newsletter issue five

AGORAPHOBIA AND PANIC VOLUNTEER ASSOCIATION (1998c) *Training manual: volunteer companion program*

AHMED, S. KILBY, J. LURY, C. MCNEIL, M & SKEGGS, B. (eds.) (2000)
Transformations: thinking through feminisms (Routledge: London and New York)

AMERICAN PSYCHIATRIC ASSOCIATION (1994) *Diagnostic and statistical manual of mental disorders, fourth edition* (American Psychiatric Association: Washington, D.C.)

AMERICAN PSYCHIATRIC ASSOCIATION (2000) *Diagnostic and statistical manual of mental disorders DSM IV-TR*, (American Psychiatric Association: Washington, D.C.)

AMIT, V. (ed.) (2000) *Constructing the field: ethnographic fieldwork in the contemporary world* (Routledge: London and New York)

ANDERSON, B. (1983) *Imagined communities* (Verso: London)

ANDERSON, K. & JACK, D. (1991) 'Learning to listen: interview techniques and analysis' in S.Gluck and D.Patai (eds) *Women's words the feminist practice of oral history* (Routledge: London and New York) pp.11-26

ANDREWS, & PETERS, (1999) *CIDI: the composite international diagnostic institute discussion paper* (World Health Organization: Geneva)

ANSELL, N. (2001) 'Producing knowledge about 'third world women': the politics of fieldwork in a Zimbabwean secondary school' *Ethics, Place and Environment* 4:2 pp.101-116

ANTONY, M.M.& SWINSON, R. P. (1996) *Anxiety disorders and their treatment: a critical review of the evidence-based literature* (Health Canada Publications: Ottawa)

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (1999a) *ADAO educational guide*

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (1999b) *ADAO newsletter issue ten*

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (2001a) *ADAO educational guide*

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (2001b) *Life potential program for young people: parent and teacher educational guide*

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (2001c) *Youth screen play*

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (2001d) *A parent's guide: youth and anxiety*

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (2002a) *The anxiety, panic and avoidance behaviour management workbook*

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (2002b) *Didactic presentation synopsis for life potential program for young people*

ANXIETY DISORDERS ASSOCIATION OF ONTARIO (2002c) *Dominic's skills: anxiety disorders treatment program for youth: project details and outline* Based on a collaborative effort with J.Gervais, S. Bouchard and N. Gagnier *Les trucs de Dominique: program de gestion du stress. le cahier des jeunes* (Outaouais Health and Social Services: Hull)

BAIER, A. (1986) 'Trust and antitrust' In *Ethics* 96 (University of Chicago Press: Chicago) pp.201-230

BAILEY, C., WHITE, C. & PAIN, R. (1999) 'Evaluating Qualitative Research: Dealing with the Tension Between 'Science' and 'Creativity' *Area* 31:2 pp.169-183

BANKEY, R. (1999) *The paradox of panic: A geographic analysis of agoraphobic experience*, unpublished thesis (Carleton University: Ottawa)

BANKEY, R. (2001) 'La donna e mobile: constructing the irrational woman' *Gender, Place and Culture* 8:1 pp.37-54

BANKEY, R (2002) 'Embodying agoraphobia; rethinking the geographies of women's fear' In Liz Bondi, Hannah Avis, Ruth Bankey, Amanda Bingley, Joyce Davidson, Rosaleen Duffy, Victoria Ingrid Einagel, Anja-Maaïke Green, Lynda Johnston, Susan Lilley, Carina Listerborn, Shonagh McEwan, Mona Marshy, Niamh O'Connor, Gillian Rose and Bella Vivat *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research* (Rowman and Littlefield: Lanham) pp.44-56.

BANKEY, R (2004) 'Agoraphobic autopathographies' In V. Raoul (ed) *Narratives of disease trauma and disability* (UBC Press: University of British Columbia)

BARCLAY, L. (2000) 'Autonomy and the social self' In C. MacKenzie, and N. Stoljar, (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press: Oxford) pp.52-71

BARKER, J. & SMITH, F. (2001) 'Power, positionality and practicality: carrying out fieldwork with children' *Ethics, Place and Environment* 4:2 pp.142-147

- BATT, S. (1994) *Patient no more: the politics of breast cancer* (Gynergy Books: Charlestown)
- BAUMAN, Z. (1993) *Postmodern ethics* (Blackwell: Oxford)
- BECK, U. (1992) *Risk society, towards a new modernity* (Sage: London)
- BECK, U. (1997) *The reinvention of politics* (Polity Press: Cambridge)
- BECK, U. (1998) *Democracy without enemies* (Polity press: Cambridge)
- BELL, D. (1995) 'Pleasure and Danger: the paradoxical spaces of sexual citizenship' *Political Geography* 14 pp.139-153.
- BENHABIB, S. (1992) *Situating the self: gender, community, and postmodernism in contemporary ethics* (Routledge: London and New York)
- BENSON, P. (2000) 'Feeling crazy: self worth and the social character of responsibility' In C. MacKenzie, and N. Stoljar, (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press: Oxford) pp.72-93
- BERLANT, L. (2000) 'The subject of true feeling: pain, privacy and politics' In S. Ahmed, J. Kirby, C. Lury, M. Mcneil & B. Skeggs *Transformations: thinking through feminisms* (Routledge: London and New York) pp.33-47
- BIRCH, M. (1998) 'Re/constructing research narratives: self and sociological identity in alternative settings' In J. Ribbens & R. Edwards (eds.) *Feminist dilemmas in qualitative research* Sage: London) pp.171-185
- BIRKE, L. (1998) 'The broken heart' In M. Shildrick and J. Price (eds.) *Vital signs: feminist reconfigurations of the bio/logical body* (University of Edinburgh Press: Edinburgh) pp.197-223
- BOCK, G. & JAMES, S. (eds.) (1992) *Beyond equality and difference* (Routledge: London)
- BONDI, L. (1998) 'Gender, class and urban space: public and private space in contemporary urban landscapes' *Urban Geography* 19:2 pp.160-185
- BONDI, L. (1999) 'Stages on Journeys: Some Remarks about Human Geography and Psychotherapeutic Practice', *Professional Geographer* 5:1 pp.11-24
- BONDI, L. (2001) 'Women and mental health: a feminist review' *Feminist Review* 68 pp.6-33
- BONDI, L., et al. (2002) *Subjectivities, Knowledges, and Feminist Geographies: The Subjects and Ethics of Social Research* (Rowman and Littlefield: Lanham)
- BONDI, L. & DOMOSH, M. (1998) 'On the contours of public space: a tale of three women' *Antipode* 30 pp.270-289

- BORDO, S. KLEIN, B. & SILVERMAN, M. K. (1998) 'Missing kitchens' In H. J. Nast & S. Pile (eds.) *Places through the body* (Routledge: London and New York) pp.72-92
- BORDO, S. (1988) 'Anorexia nervosa: psychopathology as the crystallization of culture' In I. Diamond and L. Quinby (eds) *Feminism and Foucault: reflections on resistance* (Northeastern University Press: Boston) pp.123-125
- BORDO, S. (1993) *Unbearable weight feminism, western culture and the body* (University of California Press: Berkeley)
- BOURNE, E. J. (2000) *The anxiety and phobia workbook* (New Harbinger Publications: Oakland, CA)
- BOWDEN, P. (1997) *Caring, gender sensitive ethics* (Routledge: London AND New York)
- BREHONY, K.A. (1983) 'Women and agoraphobia: a case for the etiological significance of feminine sex-role stereotype' In V. Franks and E.D. Rothblum, (eds) *The stereotyping of women* (Springer Inc.: New York) pp.112-127
- BRODY, H. (1987) *Stories of sickness* (Yale University Press: New Haven and London)
- BRONFEN, E. (1998) *The knotted subject: hysteria and its discontents* (Princeton University Press: Princeton, N.J.)
- BROWN, G. (1987) 'The empire of agoraphobia' *Representations* 20 pp.134-157
- BROWN, L. M. & GILLIGAN, C. (1992) *Meeting at the crossroads: women's psychology and girls' development* (Harvard University Press: Cambridge)
- BROWN, M. (1997) *Replacing citizenship: aids activism and radical democracy* (Guilford Press: New York)
- BROWN, M. (1999) 'Reconceptualizing public and private in urban regime theory: the case of AIDS politics' *International Journal of Urban and Regional Research* 23 pp.70-87
- BROWN, M. (2003) 'Hospice and the spatial paradoxes of terminal care' *Environment and Planning A* 35:5 pp.853-870
- BURMAN, E. (1998) *Deconstructing Feminist Psychology* (London: Sage)
- BUSFIELD, J. (2000) 'Introduction: Rethinking the sociology of mental health' *Sociology of Health and Illness* 22:5 pp.543-558.
- BUTLER, R & BOWLBY, S. (1997) 'Bodies and spaces: an exploration of disabled people's experiences of public space' *Environment and Planning D: Society and Space* 15 pp.411-433
- BUTLER, R. & PARR, H. (eds) (1999) *Mind and body spaces: geographies of illness, impairment and disability* (Routledge: London and New York)

- CALLARD, F. (2003a) 'The Taming of Psychoanalysis in Geography', *Social and Cultural Geography* 4, 285-312
- CALLARD, F. (2003b) 'Conceptualizations of Agoraphobia: implications for mental health promotion' *Journal of Mental Health Promotion* 2:4, pp.34-42
- CAPPS, L. & OCHS, E. (1995) *Constructing panic: the discourse of agoraphobia* (Harvard University Press: Cambridge)
- CARD, C. (1996) *The unnatural lottery: character and moral luck* (Temple University Press: Philadelphia)
- CARD, C. (1997) 'Gender and moral luck' In D.T Meyers (ed) *Feminist social thought: a reader* (Routledge: London and new York) pp.646-663
- CARTER, P. (2002) *Repressed spaces: the poetics of agoraphobia* (Reaction Books: London)
- CARTWRIGHT, L. (1995) *Screening the body: tracing medicine's visual culture* (University of Minnesota Press: Minneapolis)
- CHAMBLESS, D. L. & MALSON, J (1986) 'Sex, sex role stereotyping and agoraphobia', *Behaviour Research and Therapy* 24:2 pp.231-235
- CHAMBLESS, D. L. & GOLDSTEIN, A. J. (1992) 'Anxieties: agoraphobia and hysteria' In A. M. Brodsky & R. T. Hare-Mustin (eds) *Women and psychotherapy* (Guilford Press: New York) pp.113-134
- CHODOROW, N. (1978) *The reproduction of mothering: psychoanalysis and the sociology of gender* (University of California Press: Berkeley).
- CHOUINARD, V. (1997) 'Making space for disabling difference: challenging ableist geographies' *Environment and Planning D: Society and Space* 12 pp.379-387
- CHOUINARD, V. (1999) 'Life at the margins: disabled women's explorations of ableist spaces' In Elizabeth Kenworthy Teather (ed) *Embodied geographies: spaces, bodies and rites of passage* (Routledge: London and New York) pp.142-156
- CHOUINARD, V. & CORMODE, L. (1997) 'Guest editorials' *Environment and Planning D: Society and Space* 15 pp.379-390
- CHOUINARD, V. & GRANT, A. (1995) 'On being not even anywhere near 'the project'' *Antipode* 27 pp.157-166
- CHOW, R. (1992) 'Postmodern automatons' In J. Butler & J. W. Scott. (Eds) *Feminists theorize the political* (Routledge: London and New York) pp.101-120
- CODE, L. (1995) *Rhetorical spaces : essays on gendered locations* (Routledge: London and New York)
- CODE, L. (2000) 'The perversion of autonomy and subjection of women: discourses of social advocacy at century's end' In MacKenzie, C. and Stoljar, N. (eds) *Relational*

Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self (Oxford University Press: Oxford) pp.181-212

CONRADSON, D. (2003) 'Spaces of care in the city: the place of a community drop-in centre' *Social & Cultural Geography* 4:4 pp.507-525

CORMODE, L. (1997) 'Emerging geographies of impairment and disability', *Environment and Planning D: Society and Space* 15 pp.387-390

COTTERILL, P. (1992) 'Interviewing women, issues of friendship, vulnerability and power' *Women's studies international forum* 15:5/6 pp.593-606

COUSER, T. G. (1997) *Recovering bodies. illness, disability and life writing* (University of Wisconsin Press: Madison)

CRANG, M. (2001) 'Filed work: making sense of group interviews' In M. Limb and C. Dwyer (eds.) *Qualitative methodologies for geographers: issues and debates* (Arnold: London) pp.215-233

CRESSWELL, T. (1996) *In place out of place geography, ideology and transgression* (University of Minnesota Press: Minneapolis)

DA COSTA MEYER, E. (1996) 'La donna e mobile: agoraphobia, women, and urban space' In D. Agrest, P. Conway & L. K. Weisman (eds) *The sex of architecture* (Harry. N. Abrams: New York) pp.141-156

DAVIDSON, J. (2000a) '...The world was getting smaller: women, agoraphobia and bodily boundaries' *Area* 32:1 pp.31-40

DAVIDSON, J. (2000b) 'A phenomenology of fear: merleau-ponty and agoraphobic life-worlds' *Sociology of Health and Illness* 22:5 pp.640-660

DAVIDSON, J. (2001a) 'Fear and trembling in the mall' In: Isabel Dyck, Nancy Davis Lewis and Sara McLafferty (eds.) *Geographies of Women's Health* (Routledge: London & New York: Routledge) pp.213-230.

DAVIDSON, J. (2001b) "'Joking apart....': a 'processual' approach to researching self-help groups" *Social and Cultural Geography* 2:2 pp.163-183.

DAVIDSON, J. (2001c) 'Pregnant Pauses: Agoraphobic Embodiment and the Limits of (Im)Pregnability' *Gender, Place and Culture* 8:3 pp.283-297.

DAVIDSON, J. (2002) 'All in the Mind?': Women, Agoraphobia and the Subject of Self-Help', In Liz Bondi, Hannah Avis, Ruth Bankey, Amanda Bingley, Joyce Davidson, Rosaleen Duffy, Victoria Ingrid Einagel, Anja-Maaïke Green, Lynda Johnston, Susan Lilley, Carina Listerborn, Shonagh McEwan, Mona Marshy, Niamh O'Connor, Gillian Rose and Bella Vivat, *Subjectivities, Knowledges and Feminist Geographies* (London: Rowman and Littlefield) pp.15-33

DAVIDSON, J. (2003) *Phobic geographies: the phenomenology and spatiality of identity* (Ashgate: Aldershot)

- DEAR, M. & TAYLOR, S.M.(1982) *Not on our street: community attitudes to mental health care* (Pion: London)
- DEAR, M., WILTON, R., GABER, S.L., TAKAHASHI, L. (1997) 'Seeing people differently: the sociospatial construction of disability' *Environment and Planning D: Society and Space* 15:4 pp.455 - 480
- DEL CASINO, V. JR., GRIMES, A. J., HANNA, S. P., JONES III, J. P., (2000) 'Methodological frameworks for the geography of organizations' *Geoforum* 31 pp.523-528
- DESBIENS, C. (1999) 'Feminism 'in' geography, elsewhere, beyond and the politics of paradoxical space' *Gender, Place and Culture* 6:2 pp.179-185
- deSWANN, A. (1981) 'The politics of agoraphobia: on changes in emotional and relational management' *Theory and society* 10 pp.359-383
- DEUTSCH, H. (1929) 'The genesis of agoraphobia' *International journal of psychoanalysis* 10 pp.51-70.
- DEUTSCHE, R. (1996) *Evictions: art and spatial politics* (Graham Foundation: Chicago)
- DOEL, M. & SEGROTT, J. (2003) 'Self, health and gender: complementary and alternative medicine in the british mass media' *Gender Place and Culture* 10:2 pp.131-144
- DORN, M. (1998) 'Beyond nomadism: the travel narratives of a "cripple"' In Nast, Heidi J. and Pile, Steve (eds) *Places through the body* (Routledge: London and New York) pp.183-206
- DORN, M. & LAWS, G. (1994) 'Social theory, body politics and medical geography' *Professional Geographer* 46 pp.106-110
- DUBOIS, M. (1983) 'Passionate scholarship: notes on values, knowing and methods in feminist social science' In G. Bowles and R.D. Klein (eds) *Theories of women studies* (Routledge: London and New York) pp.105-116
- DUNCAN, N. (1996a) 'Renegotiating gender and sexuality in public and private spaces' In N. Duncan (ed) *BodySpace* (Routledge: London and New York) pp. 127-145
- DUNCAN, N. (1996b) *BodySpace* (Routledge: London and New York)
- DWYER, C. (1999) 'Contradictions of community: questions of identity for british muslim women' *Environment and Planning A* 31 pp.53-68
- DYCK, I. (1993) 'Ethnography: A Feminist Method?', *The Canadian Geographer* 37:1 pp.52-57.
- DYCK, I. (1995) 'Hidden geographies: the changing lifeworlds of women with multiple sclerosis', *Social Science and Medicine* 40 pp.307-320.

- DYCK, I. (1998) 'Methodology on the line: constructing meanings about 'cultural difference' in health care research' In V. Strong-Boag, G. Sherill, A. Eisenberg & J. Anderson (eds.) *Painting the maple: essays on race, gender and the construction of canada* (UBC Press: Vancouver) pp.19-36
- DYCK, I. (1999) 'Using qualitative methods in medical geography: deconstructive moments in a subdiscipline?' *Professional Geographer* 51:2 pp.243-253
- DYCK, I. (2001a) 'Who and what is Canada? construction of cultural identities in health care research' *Journal of Historical Geography* 27:3 pp. 417-429
- DYCK, I., LEWIS, N. D. & MCLAFFERTY, S. (EDS) (2001b) *Geographies of women's health* (Routledge: New York and London)
- ELSHTAIN, J. B. (1994) *Public man, private woman : women in social and political thought* (Princeton University Press: Princeton, N.J.)
- ENGLAND, K. (1994) 'Getting personal: reflexivity, positionality, and feminist research' *Professional Geographer* 46:1 pp.73-80
- FERGUSON, K. (1991) 'Interpretation and genealogy in feminism' *Signs* 16:2 pp.322-339
- FINCH, J. (1984) 'Its great to have someone to talk to: the ethics and politics of interviewing women' In H. Roberts and C. Bell (eds) *Social researching: problems, politics and practice* (Routledge: London and New York)
- FINKELSTEIN, J.(1991) *The fashioned self* (Polity Press: Cambridge)
- FOUCAULT, M. (1963) *Naissance de la clinique* (Presses Universitaires de France: Paris)
- FOUCAULT, M. (1967) *Madness and Civilization: a history of insanity in an age of reason* (Tavistock: London)
- FOUCAULT, M. (1970) *The order of things: an archaeology of the human sciences* (Pantheon Books: New York)
- FOUCAULT, M. (1972) *The archeology of knowledge and the discourse on language* (Pantheon: New York)
- FOUCAULT, M. (1975) *Surveiller et punir :naissance de la prison* (Gallimard: Paris)
- FOUCAULT, M. (1976) *The birth of the clinic: An archeology of medical perception* (Vintage books: New York)
- FOUCAULT, M. (1977) *Mental illness and psychology* [translated by Alan Sheridan] (New York: Harper and Row)
- FOUCAULT, M. (1980a) 'Questions on geography' In C. Gordon (ed) *Power/knowledge: selected interviews and other writings 1972-1977* (Harvester Press: Hemel Hempstead)

- FOUCAULT, M. (1980b) *Power/knowledge : selected interviews and other writings, 1972-1977* [edited by Colin Gordon translated by Colin Gordon et al.] (Harvester Press: Brighton, Sussex)
- FOUCAULT, M. (1984) *The Foucault reader* [edited by Paul Rabinow] (Pantheon Books: New York)
- FOUCAULT, M. (1986a) *The history of sexuality* [translated from the French by Robert Hurley] (Pantheon Books: New York)
- FOUCAULT, M. (1986b) *Foucault : a critical reader* [edited by David Couzens Hoy] (Blackwell: London)
- FOUCAULT, M. (1988) *Technologies of the self : a seminar with Michel Foucault* / edited by Luther H. Martin, Huck Gutman, Patrick H. Hutton (University of Massachusetts Press: Amherst)
- FOUCAULT, M. (1989) *Foucault live : (interviews, 1966-84)* [translated by John Johnston ; edited by Sylvère Lotringer] (Semiotext(e): New York)
- FOUCAULT, M. (1996) *Foucault live : (interviews, 1961-1984)* [edited by Sylvère Lotringer ; translated by Lysa Hochroth and John Johnston] (Semiotext(e): New York)
- FRANK, A. (1991) *At the will of the body : reflections on illness* (Houghton Mifflin: Boston)
- FRANK, A. (1995) *The wounded storyteller* (Routledge: New York and London)
- FRASER, N. (1989) *Unruly practices : power, discourse, and gender in contemporary social theory* (University of Minnesota Press: Minneapolis)
- FRIEDMAN, M. (1997) 'Beyond caring: the demoralization of gender' In D.T Meyers (ed) *Feminist social thought: a reader* (Routledge: London and New York) pp.665-679
- FRIEDMAN, M. (1987) 'Beyond caring: the demoralization of gender' *The Canadian Journal of Philosophy* 13 pp.199-218
- FRIEDMAN, M. (2000) 'Autonomy, social disruption and women' In C. MacKenzie. and N. Stoljar (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press: Oxford) pp.35-51
- GALVIN, R. (2002) 'Disturbing notions of chronic illness and individual responsibility: towards a genealogy of morals' *Health* 6:2 pp.107-137.
- GARBOWSKY, M. M. (1989) *The house without the door : a study of emily dickinson and the illness of agoraphobia* (Associated University Presses: Cranbury, N. J.)
- GARDENER, C. BROOKS (1994) 'Out of place: gender, public places and situational disadvantage' In R. Friedland & D. Boden (eds) *Now here, space time and modernity* (University of California Press: Berkeley) pp.335-355

- GARDENER, C. BROOKS (1995) *Passing by: gender and public harassment* (University of California Press: Berkeley).
- GIDDENS, A. (1991) *Modernity and self identity; self and society in the late modern age* (Polity Press: Cambridge)
- GILBERT, M. (1994) 'The politics of location: doing feminist research at home' *Professional Geographer* 46:1 pp.90-96
- GILLIGAN, C. (1982) 'In a different voice: women's conceptions of self and morality' In D.T Meyers (ed) *Feminist social thought: a reader* (Routledge: London and New York) pp.547-582
- GILLIGAN, C. (1982) *In a different voice: psychological theory and women's development* (Cambridge University Press: Harvard)
- GILMAN, S. (1993) 'The image of the hysteric' in Gilman, S., King, H., Porter, R., Rousseau G. S., & Showalter, E. (contributors) *Hysteria Beyond Freud* (University of California Press: Berkeley)
- GILMAN, S. (1995) *Health and illness: images of difference* (Reaktion Books: London)
- GILMAN, S. (1996) *Seeing the insane [introduction by Eric T. Carlson with a new after word by the author]* (University of Nebraska Press: Lincoln)
- GLASER, L. (2003) *Media induced fear and anxiety* (Published Thesis <http://cct.georgetown.edu/thesis/LaurenGlaser.pdf>)
- GLEESON, B. J. (1999) *Geographies of disability* (Routledge: London and New York)
- GLEESON, B. J. & KEARNS, R. (2001) 'Remoralising landscapes of care' *Environment and Planning D: Society and Space* 19 pp.61-80
- GROSZ, E. (1994) *Volatile bodies towards a corporeal feminism* (Indiana University Press: Indianapolis)
- HARAWAY, D.J. (1988) *Primate visions : gender, race, and nature in the world of modern science* (Routledge: London and New York)
- HARAWAY, D. (1991) *Simians, cyborgs and women: the reinvention of nature* (Routledge: New York and London)
- HAWKINS, A. H. (1993) *Reconstructing illness. studies in pathography* (Purdue University Press: Indiana)
- HAY, I. (ED) (2000) *Qualitative methods in human geography* (Oxford University Press: Oxford)
- HEKMAN, S. (1990) *Gender and Knowledge: Elements of a Post-modern Feminism* (Polity Press: Cambridge).

HELD, V. (1993) *Feminist morality : transforming culture, society, and politics* (University of Chicago Press: Chicago)

HELD, V. (1997) 'Feminism and moral theory' In D.T Meyers (ed) *Feminist social thought: a reader* (Routledge: London and new York) pp.631-645

HERTZ, R. (ED) (1997) *Reflexivity and voice* (Sage: London)

HIRSCHMAN N. & DI STEFANO, (1996) *Revisioning the political: feminist reconstructions of traditional concepts in western political theory* (Westview Press: Boulder, Colorado)

HOLLAND, J. & RAMAZANOGLU, C. (1994) 'Coming to conclusions: power and interpretation in researching young women's sexuality' In M. Maynard and J. Purvis (eds) *Researching women's lives from a feminist perspective* (Taylor and Francis: London) pp.112-145

HOOKS, B. (1990) "Choosing the margin as a site of radical openness' In *Yearning* (South End Press: Boston) pp.145-153

HORTON, J. (2001) 'Do you get some funny looks when you tell people what you do?' muddling through some angsts and ethics of (being a male) researching with children' *Ethics, Place and Environment* 4:2 pp.159-166

HOVORKA, A. (1997) 'Searching for an alternative discourse to 'development': women heads of household access to adequate housing in Harare zimbabwe' (Carleton university MA thesis)

HOWELL, P. (1993) 'Public space and the public sphere: political theory and the historical geography of modernity' *Environment and Planning D: Society and Space* 11 pp.303-322

HUTCHEON, L. (1994) *Irony's edge: the theory and politics of irony* (Routledge: London and New York)

IMRIE, R. (1996) *Disability and the city : international perspectives* (St Martin's Press: London)

JACKSON, P. (2001) 'Making sense of qualitative data' In M. Limb & C. Dwyer (eds) *Qualitative methodologies for geographers: issues and debates* (Arnold: London) pp.199-214

JONES III, J.P., NAST, H.J & ROBERTS, S.M.(EDS)(1997) *Thresholds in feminist research: difference, methodology and representation* (Routledge: London and New York)

KANGAS, I. (2001) 'Making sense of depression: perceptions of melancholia in lay narratives' *Health* 5:1 pp.76-92

KANGAS, I. (2002) "'Lay' and 'expert': illness knowledge constructions in the sociology of health and illness' *Health* 6:3 pp.301-304.

- KEARNS, R.A. (1997) 'Narrative and metaphor in health geographies' *Progress in Human Geography* 21:2 pp.269-277.
- KEARNS, R.A. (1998) 'Third sector stories: taking community seriously' *Health and Social Care in the Community* 6 pp.221-223
- KEARNS, R.A. (2000) 'Being there: research through observing and participating' In Iain Hay (ed) *Qualitative research methods in human geography* (Oxford University Press: Oxford)
- KELLER, E. F. (1985) *Reflections on gender and science* (Yale University Press: New Haven, C.T.)
- KENWORTHY TEATHER, E. (1999) 'Introduction: geographies of personal discovery' In Elizabeth Kenworthy Teather (ed) *Embodied geographies: spaces, bodies and rites of passage* (Routledge: London and New York) pp.1-26
- KENWORTHY TEATHER, E. (ED) (1999) *Embodied geographies: spaces, bodies and rites of passage* (Routledge, London and New York)
- KIERKEGAARD, S. (1980) *The Concept of Anxiety: A Simple Psychologically Orienting Deliberation on the Dogmatic Issue of Hereditary Sin* [trans. Reidar Thomte in collaboration with Albert B. Anderson] (Princeton University Press: Princeton)
- KILIAN, T. (1998) 'Public and private, power and space' In A. Light & M. J. Smith (eds.) *The production of public space* (Rowman and Littlefield Publishers Inc.: Lanham, Maryland) pp.115-134
- KIRK, S.A. & KUTCHINS, H. (1992) *The selling of DSM : the rhetoric of science in psychiatry* (A. de Gruyter: New York)
- KLEINMAN, A. (1988) *The illness narratives* (Routledge: New York and London)
- KOBAYASHI, A. (1994) 'Coloring the field: gender, "race", and the politics of fieldwork' *Professional Geographer* 46:1 pp.73-80
- KOEHN, D. (1999) *Rethinking feminist ethics: care, trust and empathy* (Routledge: London and New York)
- KROKER, A. & COOK (1985) *The postmodern scene: excremental culture and hyper aesthetics* (Macmillan Educational: London)
- KROKER, A. & KROKER, M. (1991) *The Hysterical male: new feminist theory* (New World Perspectives: Montreal)
- KUMAR, K. (1996) 'Home: the promise and predicament of private life at the end of the twentieth century' In J. Weintraub & K. Kumar (eds) *Public and private in thought and practice: perspectives on a grand dichotomy* (University of Chicago Press: Chicago) pp. 204- 220

- LAL, J. (1996) 'Situating locations: the politics of self, identity and other in living and writing the text' In D. Wolf (ed) *Feminist dilemmas in fieldwork* (Westview Press: Boulder, Colorado) pp.185-214
- LAURIE, N. DWYER, C. HOLLOWAY, S. & SMITH, F. M. (1999) *Geographies of new femininities*. (Longman: Harlow)
- LIMB, M. & DWYER, C. (EDS) (2001) *Qualitative methodologies for geographers: issues and debates* (Arnold: New York)
- LEDER, D. (1990) *The absent body* (University of Chicago Press: Chicago)
- LEDER, D. (ED)(1992) *The body in medical thought and practice* (Kluwer Academic Publishers: Dordrecht and Boston)
- LEY, D. & MOUNTZ, A. (2001) 'Interpretation, representation, positionality: issues in field research in human geography' In M. Limb & C. Dwyer (eds) *Qualitative methodologies for geographers: issues and debates* (Arnold: London) pp.234-247
- LIGHT, A. & SMITH, J. M. (eds) (1998) *The production of public space* (Rowman and Littlefield Publishers Inc.: Lanham, Maryland)
- LISTER, R. (1997) *Citizenship: feminist perspectives* (Arnold: London) London & New York).
- LISTER, R. (1998) 'Citizen in action: citizenship and community development in a northern ireland context' *Community Development Journal* 33:3 pp.226-235
- LISTER, R. (2001a) 'Towards a citizen's welfare state: the 3+2 r's of welfare reform' *Theory, Culture and Society* 18:2-3 pp.91-111
- LISTER, R. (2001b) 'Citizenship and gender' In K. Nash and A. Scott (eds) *Blackwell companion to Political Sociology* (Blackwell: Oxford)
- LONGHURST, R. (1999) 'Attempts to impose limits: the disorderly bodies of pregnant women' In E. Kenworthy Teather (ed.) *Embodied Geographies: Spaces, Bodies and Rites of Passage* (Routledge: London and New York)
- LONGHURST, R. (2000) 'Corporeographies of Pregnancy: 'Bikini Babes'' *Environment and Planning D: Society and Space*, 18:4 pp.453-472
- LONGHURST, R. (2001) *Bodies: exploring fluid boundaries* (Routledge: London and New York)
- LUPTON, D. (1994) *Medicine as culture: illness, disease and the body in western societies* (Sage: London)
- LUPTON, D. (1995) *The imperative of health: public health and the regulated body* (Sage: London)
- LUPTON, D. (1999a) *Risk* (Routledge: London and New York)

LUPTON, D. (1999b) *Risk and sociocultural theory: new directions and perspectives* (Cambridge University Press: Cambridge)

MACKAY, F. (2001) *Love and politics: women politicians and the ethic of care* (Continuum: London and New York)

MACKENZIE, C. & STOLJAR, N. (eds) (2000) *Relational autonomy: feminist perspectives on autonomy, agency and the social self* (Oxford University Press: Oxford)

MACKENZIE, C. (2000) 'Imagining oneself otherwise' In MacKenzie, C. and Stoljar, N. (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press: Oxford) pp.124-150

MADGE, C. RAGHURAM, P. SKELTON, P. WILLIS, K. & WILLIAMS, J. (1997) 'Methods and methodologies in feminist geographies: politics, practice and power' In Women And Geography Study Group *Feminist geographies: explorations in diversity and difference* (Addison Wesley Longan: Essex) pp.86-111

MATTHEWS, H., TAYLOR, M. & LIMB, M. (1998) 'The geography of childhood: some ethical and methodological considerations for project and dissertation work' *Journal of geography in Higher Education* 22 pp.311-324

MAUTHNER, N. & DOUCET, A. (1998) 'Reflections on a voice-centered relational method: analyzing maternal and domestic voices' In J. Ribbens & R. Edwards (eds.) *Feminist dilemmas in qualitative research: public knowledge and private lives* (Sage: London) pp.119-145

MAY, R. (1977) *The meaning of anxiety* (W.W. Norton: New York)

MCLEOD & SHERWIN, S. (2000) 'Relational Autonomy, Self-Trust, and Health Care for Patients Who are Oppressed' In C. MacKenzie and N. Stoljar (eds) *Relational Autonomy: feminist perspectives on autonomy, agency and the social self* (Oxford University Press: Oxford) pp.259-279

MCNALLY, R. J. (1994) *Panic disorder: a critical analysis* (Guilford Press: New York)

MEYERS, D. T. (1989) *Self, society and personal choice* (Columbia University Press: New York)

MEYERS, D. T. (1997) *Feminist social thought: a reader* (Routledge: London and New York)

MEYERS, D. T. (2000) 'Intersectional identity and the authentic self?: opposites attract!' In MacKenzie, C. and Stoljar, N. (eds) *Relational autonomy: feminist perspectives on autonomy, agency and the social self* (Oxford University Press: Oxford) pp.151-180

MICALE, M. (1995) *Approaching hysteria: disease and its interpretations* (Princeton University Press: Princeton, N.J.)

MILLIGAN, C. (1999) 'Without these walls: a geography of mental ill-health in a rural environment' In R. Butler and H. Parr (eds) *Mind and Body spaces: geographies of illness, impairment and disability* (Routledge: London and New York) pp. 221-239

MOHAN, J.F. (1998) 'Explaining geographies of health care: a critique' *Health and Place* 4:2 pp.113-124

MOORE, B. & WISMER, (1994) 'Communities, Work and Public/Private Sphere Models' *Gender, Place and Culture* 1:1 pp.71-89

MORRIS-ROBERTS, K. (2001) 'Intervening in friendship exclusion? the politics of doing feminist research with teenage girls' *Ethics, Place and Environment* 4:2 pp.147-153

MOSS, P. (1995) 'Reflections on the 'gap' as part of the politics of research design' *Antipode* 27:1 pp.82-90

MOSS, P. & DYCK, I. (1996) 'Inquiry into environment and body: women, work and chronic illness' *Environment and Planning D: Society and Space* 14 pp.737-753

MOSS, P. & DYCK, I. (1999a) 'Body, corporeal space, and legitimating chronic illness: women diagnosed with M.E.' *Antipode* 31:4 pp.372-397

MOSS, P. & DYCK, I. (1999b) 'Journeying through M.E.: identity, the body and women with chronic illness' In Elizabeth Kenworthy Teather (ed) *Embodied geographies: spaces, bodies and rites of passage* (Routledge, London and New York) pp.157-174

MOUFFE, C. (ED)(1992) *Dimensions of radical democracy : pluralism, citizenship, community* (Verso: London)

MOUFFE, C. (1993) *The Return of the Political* (Verso: London and New York)

MOUFFE, C. (1997) 'Feminism, citizenship and radical democratic politics' In D. T. Meyers (ed.) *Feminist social thought: a reader* (Routledge: London and New York) pp.532-546

NAIR, Y. (2000) 'Dead images, live transmissions: greg lougainis and the construction of AIDS on television' *Discourse* 22:1 pp.53-69

NANCY, J. L. (1991) *The inoperative community* (University of Minnesota Press: Minneapolis, MN)

NAST, H. J. (1994) 'Opening remarks on 'women in the field'' *Professional Geographer* 46:1 pp.54-66

NAST, H. J. & PILE, S. (EDS) (1998) *Places Through the Body* (Routledge: London and New York)

NATIONAL INSTITUTE OF MENTAL HEALTH (2003) *Brochure on anxiety* (Department of Health and Public Services, Public Health service, National Institutes of Health; Bethesda, MD)

NEDELSKY, J. (1991) *Feminist theory: challenges to legal and political thought* (University of Toronto: Toronto)

NELSON, H.L. (ED) (1997) *Stories and their limits: narrative approaches to bioethics* (Routledge: London and New York)

NODDINGS, N. (1984) *Caring: a feminine approach to ethics and moral education* (University of California Press: Berkeley)

OAKLEY, A (1981) 'Interviewing women: a contradiction in terms' In H. Roberts (ed) *Doing feminist research* (Routledge: London and New York)

OBERHAUSER, A.M. (1997) 'Home as 'field': households and homework in rural appalachia' In J.P. Jones III, H.J. Nast and S.M. Roberts (eds) *Thresholds in feminist research: difference, methodology and representation* (Routledge: London and New York) pp.165-183

OKIN, S. M. (1989) *Justice, Gender and the Family* (Basic Books: New York) Oxford and New York)

PARK, D. C. & RADFORD, J. P (1997) 'Space, place and the asylum: an introduction' *Health & Place* 3:2 pp.71-72

PARK, D. C., RADFORD, J. P. & VICKERS, M. H. (1998) 'Disability studies in human geography' *Progress in Human Geography* 22: 2 pp.208-233.

PARR, H. (1997) 'Mental health, public space and the city: questions of individual and collective access' *Environment and Planning: Society and Space* 15:4 pp.435-454

PARR, H (1998a) 'Mental health, ethnography and the body' *Area* 30:1 pp.28-37

PARR, H. (1998b) 'The politics of methodology in 'post-medical geography': mental health research and the interview' *Health &Place* 4 pp.341-353.

PARR, H. (1999a) 'Bodies and psychiatric medicine: interpreting different geographies of mental health' In R. Butler & H. Parr (eds) *Mind and body spaces: geographies of illness, impairment and disability* (Routledge: London and New York) pp.119-137

PARR, H. (1999b) 'Delusional Geographies: The Experiential Worlds of People During Madness / Illness' *Environment and Planning D: Society and Space* 17 pp.673-690.

PARR, H. (2000) 'Interpreting the Hidden Social Geographies of Mental Health: Ethnographies of Inclusion and Exclusion in Semi-Institutional Places' *Health &Place* 6 pp.225-237.

PARR, H. (2001) 'Negotiating different ethnographic contexts and building geographical knowledges: empirical examples from mental-health research' In M. Limb & C. Dwyer (eds) *Qualitative methodologies for geographers: issues and debates* (Arnold: London) pp.181-195

PARR, H. (2002a) 'New body-geographies: the embodied spaces of health and illness information on the Internet' *Environment and Planning D: Society and Space* 20 pp.73-95

- PARR, H. (2002b) 'Medical Geography: diagnosing the body in medical and health geography, 1999-2000' *Progress in Human Geography* 26:2 pp.240-251.
- PARR, H. & PHILO, C. (1995) 'Mapping Mad Identities', in: S. Pile & N. Thrift (eds) *Mapping the subject: geographies of cultural transformation* (Routledge: London and New York)
- PATAI, D. (1991) *Women's words : the feminist practice of oral history* (Routledge: London and New York)
- PATEMAN, C. (1988) *The sexual contract* (Polity Press: Cambridge)
- PATEMAN, C. (1989) *The disorder of women* (Stanford University Press: Stanford)
- PETERSEN, A. (1996) 'The healthy city, expertise, and the regulation of space' *Health & Place* 2:3 pp.157-165.
- PETERSEN, A. & LUPTON, D. (1998) *The new public health* (Sage: London)
- PHELAN, S. (1989) *Identity politics : lesbian feminism and the limits of community* (Temple University Press: Philadelphia)
- PHILLIPS, A. (1995) *The politics of presence* (Oxford University press: Oxford)
- PHILO, C. (1997) 'Across the Water: reviewing geographical studies of asylums and other mental health facilities' *Health and Place* 3:2 pp.73-89
- PHILO, C. (2000) 'The Birth of the Clinic: an Unknown work of medical geography' *Area* 32:1 pp.11-19
- PHILO, C. (1995) 'Journey to the asylum: a medical geographical idea in historical context' *Journal of historical geography* 21 pp.148-168
- PILE, S. & THRIFT, N. (1995) *Mapping the subject : geographies of cultural transformation* (Routledge: London and New York)
- PORTER, R. (2001) *Bodies politic: disease, death, and doctors in Britain, 1650-1900* (Cornell University Press: Ithaca, N.Y.)
- PORTER, R. (2002) *Madness: a brief history* (Oxford University Press: Oxford)
- PRATT, G. (2000) 'Research performances' *Environment and Planning D: Society and Space* 18 pp. 639-651
- PRICE, J. & SHILDRICK, M. (1998) 'Uncertain thoughts on the dis/abled body' In M. Shildrick and J. Price (eds) *Vital signs: feminist reconfigurations of the bio/logical body* (University of Edinburgh Press: Edinburgh) pp.224-249
- PUNCH, S. (2001) 'Multiple methods and research relations with children in rural bolivia' In M. Limb & C. Dwyer (eds) *Qualitative methods for geographers: issues and debates* (Arnold: New York) pp.165-180

- RACHMAN, S. (1998) *Anxiety* (Psychology Press: Sussex)
- RAMAZANOGLU, C. & HOLLAND, J. (2002) *Feminist methodology : challenges and choices* (Sage: London)
- RAWLS, J. (1971) *A theory of justice* (Harvard University Press: Cambridge)
- REINHARTZ, S. (1992) *Feminist methods in social research* (Oxford University Press: Oxford)
- REINHARTZ, S. (1997) 'Who am I? the need for a variety of selves in the field' In V.Amit (ed) *Constructing the field: ethnographic fieldwork in the contemporary world* (Routledge: London and New York)
- HERTZ, R. (ED) *Reflexivity and Voice* (Sage: London) pp.3-20
- REUTER, S. (2002) 'Doing agoraphobia(s): a material-discursive understanding of diseased bodies' *Sociology of health and illness* 24 pp.750-770
- RIBBENS, J. & EDWARDS, R. (1998) *Feminist dilemmas in qualitative research: public knowledge and private lives* (Sage: London)
- RICHARDS, R. (1996) *Mental Illness and Personality* (Westview Press: Boulder, Colorado)
- RIMKE, H. M. (2000) 'Governing citizens through self help literature' *Cultural Studies* 14:1 pp.61-78
- ROBSON, E. (2001) ' Interviews with the tears? exploring dilemmas of research with young carers in Zimbabwe' *Ethics, Place and Environment* 4:2 pp.135-141
- ROONEY, E. (2002) 'A semiprivate room' *Differences: A Journal Of Feminist Cultural Studies* 13:1 pp. 128-157
- ROSE, G. (1993) *Feminism and geography: the limits of geographical knowledge* (Polity Press: Cambridge).
- ROSE, G. (1997) 'Situating knowledges: positionalities, reflexivities and other tactics' *Progress in Human Geography* 21 pp.305-320
- ROSE, N. (1992) 'Governing the enterprising self' In P. Heelas and P.Morris (eds) *The values of enterprise culture: the moral debate* (Routledge: London and New York) pp.141-164
- RUDDICK, S. (1989) *Maternal thinking* (Beacon Press: Boston)
- SCOTT, A. (1999) 'Paradoxes of holism: some problems in developing an anti oppressive medical practice' *Health* 3:2 pp.131-149
- SEVENHUIJSEN, S. (1998) *Citizenship and the ethics of care: feminist considerations on justice, morality and politics* (Routledge: London and New York)

SHANLEY, M. L. & NARAYAN, U. (eds.) (1997) *Reconstructing political theory* (Polity Press: Cambridge)

SHANLEY, M. L. & PATEMAN, C. (eds.) (1994) *Feminist interpretations and political theory* (Polity Press: Cambridge)

SHAW, (2002) 'How lay are lay beliefs?' *Health* 6:3 pp.287-299

SHERWIN, S. (1988) 'Chapter One: Introduction' and 'Chapter Two: A Relational Approach to Autonomy in Health Care' In The Feminist Health Care Ethics Research Network, Susan Sherwin Coordinator *The Politics of Women's Health: Exploring Agency and Autonomy* (Temple University Press: Philadelphia)

SHILDRICK, M. & PRICE, J (1998) *Vital signs: feminist reconfigurations of the bio/logical body* (University of Edinburgh Press: Edinburgh)

SHILDRICK, M. & PRICE, J. (1998) 'Vital signs: texts, bodies and biomedicine' In M. Shildrick and J. Price (eds.) *Vital signs: feminist reconfigurations of the bio/logical body* (University of Edinburgh Press: Edinburgh) pp.1-17

SHOWALTER, E. (1987) *The Female Malady: Women, Madness and English Culture* (London: Virago).

SHOWALTER, E. (1997) *Hystories: hysterical epidemics and modern media* (Columbia University Press: New York)

SKEGGS, B. (2000) 'Introduction' In S. Ahmed, J. Kilby, C. Lury, M. Mcneil & B. Skeggs (eds) *Transformations: thinking through feminisms* (Routledge: London and New York) pp.27-32

SKEGGS, B. (1994) 'Situating the product of feminist ethnography' In M. M. and J. Purvis (eds) *Researching Women's Lives from a Feminist Perspective* (Taylor & Francis: London)

SKEGGS, B. (ED) (1995) *Feminist cultural theory: process and production* (Manchester University Press: Manchester)

SMAIL, D.J. (1998) *Taking care: an alternative to therapy* (Constable: London)

SMITH, D. (1987) *The everyday world as problematic: A feminist sociology* (University of Toronto Press: Toronto)

SMITH, S. (1993) 'Who's talking/who's talking back? The subject of personal narrative' *Signs* 18:2 pp.392-407

SMITH, S. (2001) 'Doing qualitative research: from interpretation to action' In M. Limb & C. Dwyer (eds.) *Qualitative methodologies for geographers: issues and debates* (Arnold: London) pp.23-40

SONTAG, S. (1978) *Illness as Metaphor* (Farrar, Straus and Giroux: New York)

- SQUIRES, J. (1994) 'Private lives, secluded places: privacy as political possibility' *Environment and Planning D: Society and Space* 12 pp.387-401
- SQUIRES, J. (2001) 'Representing groups, deconstructing identities' *Feminist Theory* 2:1 pp.7-27
- STAEHELI, L. (1997) 'Publicity, privacy, and women's political action' *Environment and Planning D: Society and Space* 14 pp.601-619
- STAEHELI, L. (2003) 'Women and the work of community' *Environment and Planning A* 35:5 pp.815 - 831
- STAEHELI, L. A. & LAWSON, V. A. (1994) 'A discussion of 'women in the field': the politics of feminist fieldwork' *Professional Geographer* 46:1 pp. 96-102.
- STANDING, K. (1998) 'Writing the voices of the less powerful: research on lone mothers' In J. Ribbens and R. Edwards (eds) *Feminist dilemmas in qualitative research: public knowledge and private lives* (Sage: London) pp.186-201
- STANLEY, L. (1992) *The auto/biographical I : the theory and practice of feminist auto/biography* (Manchester University Press: Manchester)
- STANLEY, L. (ED) (1997) *Knowing feminisms, on academic borders, territories and tribes* (Sage: London)
- STANLEY, L. & WISE, S. (1993) *Breaking out: feminist consciousness and feminist research* (Routledge" London and New York)
- STURKEN & CARTWRIGHT, L. (2001) *Practices of looking : an introduction to visual culture* (Oxford University Press: Oxford and New York)
- SYMONDS, A. (1973) 'Phobias after marriage: women's declaration of dependence' In *Psychoanalysis and women* (Brunner/Mazel: New York) pp.228-239
- TAKAHASHI, I.M. (2000) 'Representation, attitudes and behaviour, analyzing the spatial dimensions of community response to mental disability' *Environment and Planning A* 32:4 pp.581-598
- TAYLOR, S.M. (1989) 'Community exclusion of the mentally ill' In J. Wolch and M. Dear (eds) *The power of geography: how territory shapes social life* (Unwin Hyman: London)
- THE PROFESSIONAL GEOGRAPHER (1994) *Special Issue: Women in the field: Critical Feminist Methodologies and Theoretical Perspectives* 46:1 pp.54- 102
- TRONTO, J. (1993) *Moral boundaries: A political argument for an ethic of care* (Routledge: London and New York)
- TRONTO, J (1996) 'Care as a political concept' In N.J. Hirschmann and C. Di Stefano *Revisioning the political: feminist reconstructions of traditional concepts in western political theory* (Westview Press: Boulder, Colorado) pp.139-156

- TUAN, Y.F (1979) *Landscapes of fear* (Blackwell, Oxford)
- TUANA, N. (1993) 'With many voices, feminism, theoretical pluralism' In P. England (ed) *Theory of gender/feminism on theory* (Aldine de Gruyer: New York) pp.281-299
- TURNER, B. (1987) *Medical Power and Social Knowledge* (Sage: London)
- TURNER, B. (1994) *Regulating bodies: essays in medical sociology* (Routledge: London and New York)
- USSHER, J.(1989) *Critical psychology: the psychology of the female body* (Routledge: London and New York)
- USSHER, J. (ED) (1997) *Body talk: the material and discursive regulation of sexuality, madness, and reproduction* (Routledge: London and New York)
- VAN DIJCK, J. (1998) *Imagenation :popular images of genetics* (New York University Press: New York, N.Y.)
- VASSELEU, C. (1998) 'The mouth and the clinical gaze' In M. Shildrick and J. Price (eds) *Vital signs: feminist reconfigurations of the bio/logical body* (University of Edinburgh Press: Edinburgh) pp.66-77
- VIDLER, A. (1993) 'Bodies in space/subjects in the city: psychopathologies of modern urbanism' *Differences: a journal of feminist cultural studies* 5:3 pp.31-51
- WALKER, J. NORTON, R. G. & ROSS, C. A. (eds) (1991) *Panic disorder and agoraphobia a comprehensive guide for the practitioner* (Brooks/Cole Publishing Co.: California)
- WALKER, N. (1990) *Feminist alternatives: irony and fantasy in the contemporary novel by women* (University press of Mississippi: Jackson and London)
- WEINTRAUB, J. (1996) 'The theory and politics of the public/private distinction' In J. Weintraub & K. Kumar (eds) *Public and private in thought and practice: perspectives on a grand dichotomy* (University of Chicago Press: Chicago) pp.1- 42
- WEINTRAUB, J. & KUMAR, K. (EDS) (1996) *Public and private in thought and practice: perspectives on a grand dichotomy* (University of Chicago Press: Chicago)
- WESTPHAL, K.O. (1872) 'Die agoraphobie: eine neuropathische ercheinung' *Archivfur psychiatrie und nervenkrankheiten* 3 pp.131-61
- WILES, J. & ROSENBERG, M. W. (2001) "'Gentle Caring Experience' seeking alternative health care in Canada' *Health & Place* 7 pp.209-224
- WILKINSON, I. (2001) *Anxiety in a risk society* (Routledge: London and New York)
- WILLIAMS S. J. & BENDELOW, G. (1998) *The Lived Body: Sociological Themes, Embodied Issues* (Routledge: London and New York)

- WILSON, K. (2003) 'Therapeutic landscapes and first nations peoples: an exploration of culture, health and place' *Health & Place* 9 pp.209-224
- WOLCH J. & PHILO, C. (2000) 'From distributions of deviance to definitions of difference: past and future mental health geographies' *Health & Place* 6 pp.137-157
- WOLF, D. L. (1996) *Feminist dilemmas in fieldwork* (Westview Press: Boulder)
- WOMEN AND GEOGRAPHY STUDY GROUP (1997) *Feminist geographies: explorations in diversity and difference* (Longman: London)
- YOUNG, I. M. (1990) *Justice and the politics of difference* (Princeton University Press: Princeton)
- YOUNG, I.M. (1997) 'Difference as a resource for democratic communication' In J. Bohman and W. Rehg (eds) *Deliberative democracy: essays on reason and politics* (MIT Press: Cambridge, MA) pp.383-407.
- YOUNG, I. M. (2000) *Inclusion and democracy* (Oxford University press: Oxford)